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Molloy College

Barbara H. Hagan School of Nursing.

Ph.D. in Nursing

Parents Raising Children with Intellectual/Developmental Disabilities in Jamaica:

A Grounded Theory Approach

A Dissertation by

Maureen Lowers-Roach

Submitted in partial fulfillment of the requirement for the degree of

Doctor of Philosophy

2021

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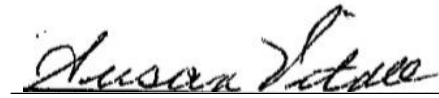
The dissertation committee of the Barbara H. Hagan School of Nursing and Health Sciences has examined the dissertation titled

PARENTS RAISING CHILDREN WITH INTELLECTUAL/DEVELOPMENTAL
DISABILITIES IN JAMAICA: A GROUNDED
THEORY APPROACH

Presented by MAUREEN LOWERS-ROACH

A candidate for the degree of Doctor of Philosophy

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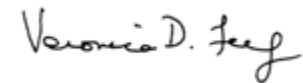
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Abstract

Purpose

The purpose of this study was to explore the experiences and/or challenges of parents or guardians of school-aged children who have intellectual and/or developmental disabilities (IDD) and are living in Jamaica.

Background

Raising a child with IDD can be overwhelming for parents and families, as it may drain them financially, emotionally, psychologically, and socially. Due to the relative poverty and scarcity of adequate resources in Jamaica, the burden of caring for a child with special needs may be challenging. Attitudes toward persons with disabilities are negative in Jamaica. Although several laws are designed to protect children with disabilities, there are still legal exclusions negatively impacting children and adults with developmental disabilities. Culture influences how parents raise their children and how they may be affected by raising a child with IDD.

Method

A qualitative method of grounded theory to uncover an in-depth analysis of caregiver challenges of parents with children who have IDD. A diverse purposive sample was obtained of 21 parents and guardians raising school-aged children with IDD. Children in the study ranged from 3 to 18 years old. The interviews were recorded, transcribed, and analyzed into concepts and constructs to develop a grounded theory.

Results

Lack of support and services was identified as the basic social problem and the core concept as the challenges they face. The lack of support and services was a sense of disappointment for parents and guardians, without which they felt no hope or normalcy for their children. They found a lack of health care professional support, empathy, and understanding. Five

supportive theoretical constructs surround the core concept of the challenges they face: Burden, It's Challenging, Emotional and Mental Well-Being, Professional Awareness, and Social Stigma.

Conclusion

Despite differences, there were shared elements in their experiences and challenges. Children with a disability bring multiple challenges to parents such as additional financial burdens, dealing with the child's problematic behavior, social stigma, and societal issues.

Dedication

This research study is dedicated to my nephew Akiel who has inspired me. To my Aunt Dorrel who encouraged me to always do my best but unfortunately did not get to witness my best (1951-2020). I would also like to dedicate this study to the mothers who face the daily challenges in caring for their children who have intellectual/developmental disabilities. The following song by Alaine (Hughes, 1990) may inspire the reader to understand the burden of mothers with children who have IDD and are living in Jamaica.

Mama

You gave me life
And taught me how to live it And
how to crawl
How to walk, how to run
You gave me love
And taught me how to give
And made me believe I could fly

And everything you did for me
You did it all the way
Never held back anything With
open arms, you help me, Kept
me safe

Dried every tear from my eye
And so I dedicate my life to you
To always make you proud
(always make you proud)
And every day I wake
I pray that God will keep you
safe and sound

Mama, you are the one that I
sing to
The one that I cling to The
love that's brought me
through

Mama, you are my shoulder to
lean on
The love that's kept being strong
Your love will carry on

Mama, you shining light Down
the dark nights
Got a view of my whole life
Made everything alright

I am blessed because you are
my Mama

And even when I made mistakes
You never leave me alone
I felt your company
Somehow you always find a
way

To make everything okay
And when I didn't know
Which road to take
You told me to follow my dreams
I am all that I am today
Because of your faith in me
And so I dedicate my life to you
To always make you proud
(always make you proud)

And every day I wake
I pray that God will keep you
safe and sound
And I am all so grateful for you
Love you unconditionally

Everything you are is who I hope
to be
Mama, you are the one that I
sing to
The one that I cling to The
love that's brought me
through

Mama, you are my shoulder to
lean on
The love that's kept on being
strong
Your love will carry on

Mama, you shining light
Down the dark nights
Got a view of my whole life
Made everything alright

I am blessed because you
are my Mama

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in raising your child with a disability.

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Chapter 1: Introduction

Caring for children with intellectual and developmental disabilities (IDD) can be overwhelming for parents and families, as it may drain them financially, emotionally, psychologically, and socially. According to the Americans with Disabilities Act in 1990, a *disability* is a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, learning, reading, concentrating, thinking, communicating, and working. Individuals with IDD include a wide range of diagnoses and problems best identified by the Bill of Rights Act of 2000 (see Table 1). Such disabilities are inclusive of cognitive, intellectual, and other deficiencies.

In the Jamaican context, according to the Disabilities Act of 2014, a person with a disability includes “a person who has a long-term physical, mental, intellectual, or sensory impairment which may hinder his full and effective participation in society, on an equal basis with other persons (Convention of the Rights of Persons with Disabilities, 2018, p. 5).” In light of this definition, as of September 2017, the Jamaica Council of Persons with Disabilities (2017) recorded a total of 38,792 registered persons with disabilities ranging from visual and hearing impairment, intellectual, physical, speech, mental illness, deafness, blindness, and a combination of two or more types. Of the 38,792 registered persons with disabilities, there were 11,844 who have a physical disability, which is the largest recorded type of disability in Jamaica. The second-largest category of disability is intellectual, with 7,211 persons recorded. The number of persons reported as having multiple disabilities was 1,610. These numbers reflect a problem that is not unique to Jamaica and may have an impact on parents who face the challenges of caring for their children.

Table 1. Definition of Developmental Disability Assistance and Bill of Rights Act of 2000

DEVELOPMENTAL DISABILITY.

- (A) **IN GENERAL.** The term “developmental disability” means a severe, chronic disability of an individual that
- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (ii) is manifested before the individual attains age 22;
 - (iii) is likely to continue indefinitely;
 - (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - (I) Self-care.
 - (II) Receptive and expressive language.
 - (III) Learning.
 - (IV) Mobility.
 - (V) Self-direction.
 - (VI) Capacity for independent living.
 - (VII) Economic self-sufficiency;

and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

- (B) **INFANTS AND YOUNG CHILDREN.** An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.
-

The World Health Organization (2011) estimated that there are 600 million persons with disabilities (PWDs) globally. Even though the statistical data available has international inconsistencies based on different definitions and methodologies for calculating populations of PWDs, the overwhelming consensus is that PWDs are estimated to represent 10% of the world's population. Data from the Jamaican Population and Census, 2001, indicated that there were 162,800 persons with disabilities living in Jamaica, of which children (0-14 years old) comprised

21% of the population (UNICEF, 2017).

The census information is an estimate and represents only reported cases, subject to intentional and unintentional under-reporting on the part of respondents. Reporting may be based on misunderstandings of what constitutes a disability and cultural issues of isolation and fear, causing families to hide PWDs (World Bank, 2016). The Statistical Institute of Jamaica has 580,000 persons registered as disabled in Jamaica. Currently, however, just 30,000 of them are registered with the Jamaican Council of Persons with Disabilities, of whom 5,000 are children (UNICEF, 2017). This discrepancy indicates the complexity of issues associated with reporting and/or providing services to PWDs that need to be uncovered through research.

In 2007, Jamaica became the first nation in the world to sign the United Nations Convention on the Rights of Persons with Disabilities; however, domestically progress, in terms of service delivery, access to healthcare, mobility, housing, training/education, recreation, employment, and positive outcomes have been very slow. The difficulty of children with disabilities has gone unnoticed in many situations as evidenced by the limited number of schools and facilities for children with disabilities in Jamaica. Children with disabilities in Jamaica may face multiple challenges, including reduced quality of care by their caregivers and limited access to health professionals and educators. Many children who have physical disabilities have mobility challenges, and hence, their ability to interact with their peers is significantly affected. In most instances, they are left to play alone and hardly attend school. Many times, they are locked up in their homes as the caregivers do their daily activities, leaving them to spend the day at home without any activity (Convention on the Rights of Persons with Disabilities, 2018). There is a lack of literature on the delivery of services to people living with disabilities as well as their caregivers in most communities (Adnams, 2010).

Despite the growing number of identified children with disabilities living in Jamaica, few schools exist in Jamaica to serve children with disabilities, and the schools where staff has been trained in meeting the needs of this population are overcrowded (Wilson, 2011). An initiative was started by the Minister of Labor and Social Security to create a registry of the number of children requiring assistance from the Ministry's Early Stimulation Program (Patterson, 2012). This program began in 1975, and as of 2012, it served 105 children with special needs such as Down syndrome, cerebral palsy, learning disabilities, behavior problems, and intellectual disability (deemed mental retardation in Jamaica). The program was developed to provide assessment and early intervention for children from birth to six years old. It was found that despite many people perceiving education to be an intrinsic right and that children with disabilities should be integrated within the general education system, there remained significant barriers to the full access and integration of children with disabilities in these institutions (Morris, 2011). However, there has been an intentional effort to promote and support the education of children with disabilities. In the academic year 2015/16, a special education curriculum was provided to 3,402 students in Jamaica with special needs (Planning Institute of Jamaica, 2018). In addition, there has been the ongoing capacity building of special education teachers and caregivers contracted to work alongside students with disabilities in mainstream educational settings (Planning Institute of Jamaica, 2018).

Stigma toward disabilities was found to be quite prevalent in 2009 as challenges caregivers face (Parnes et al., 2009). Many caregivers were also found in 2002 to not have the basic knowledge of how to deal with caregiving for children with disabilities (Nelson, 2002). Negative terminologies such as "dumb," "invalid," "handicapped," or "abnormal" are often associated with PWDs in Jamaica. Location, the severity of the disability, and ease of movement

were found to influence the levels of negative attitude and stigma toward PWDs (World Bank, 2016). A report by the World Health Organization and the World Bank reveals that people with disabilities are more than two times likely as children and adults without disabilities to have health care providers with skills that are inadequate to meet their needs (World Health Organization, 2005). These evaluative criteria prevent PWDs from reaching their full potential or engaging in activities deemed the norm for others.

Significance

This study proposes to explore how parents of children who have IDD describe their experiences of raising their children in Jamaica. Within the Jamaican culture, parents may or may not view their parenting needs through a lens of burden as they navigate the challenges of parenting. Through the understanding of the parents' experience and challenges, nurses may learn how they can offer new services or better assist in the coordination of care. This study offers a unique opportunity to inform nurses and other medical caregivers as to the central issues that need to be addressed in providing support to families where a child with IDD is present.

Problem Statement

Although there is literature on parental caregiving burden related to having a child with a developmental disability (Thorburn, 2008), not much has been researched about the caregiver burden of parents with children with IDD who are living in Jamaica. Research by Marsack-Topolewski and Church (2019) has indicated that over time, the impact of developmental, emotional, and financial burdens on the quality of life of parents dealing with children and young adults with IDD is enormous, but relatively little in-depth research has been conducted specifically focused on caregivers of children with IDD.

Neely, Barnes, and Dia (2016) have stated that children with disabilities receive most of

their support from families, with the majority of such support coming from mothers, although fathers and grandparents are increasingly responsible for providing such care, particularly when a mother works outside the home. The impact of the child's problems or care needs on families may be, according to these researchers, key predictors of negative family impact. Abbeduto et al. (2004) identified the impact of childhood disability on parents, particularly mothers and reported that literature has tended to emphasize maternal coping strategies, family functioning, and marital adjustment rather than the psychological burden and well-being of the caregivers themselves.

Cultural differences in family impact are significant in terms of their influence on coping ability (Blacher & McIntyre, 2006). The literature specific to caregiving burden does not specifically address cultural issues that are related to the burden of parents of children with IDD living in Jamaica, a finding that the Jamaican Association on Intellectual Disabilities (2019) has emphasized.

Purpose of the Study

The purpose of this study was to understand the parental experience and caregiving challenges of raising children who have IDD and are living in Jamaica. An additional goal was to explore how parents' needs evolved over the child's school-age years, in their own words. Through in-depth interviews of their parenting experiences, this qualitative approach developed a theory through methodical gathering and analysis of the data.

Research Question

This study sought to examine the following research question: What are the parents' caregiving experiences and challenges in raising children who have developmental disabilities and are living in Jamaica?

Definition of Key Terms

The following terms were used within this research study and are defined as follows:

Caregiver Burden – Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill or disabled family member (Stucki & Mulvey, 2000). It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience. Caregiver burden has been described as both observable and perceived. The objective burden is an observable, concrete, and tangible cost to the caregiver for taking care of the recipient. Subjective burden refers to the perceived costs, such as the extent to which the caregiver is burdened by performing these tasks and the positive or negative feelings experienced while giving care (Jones, 1996). The caregiver's perception of the burden, rather than the perception of other family members or healthcare providers, determines the impact on his or her life. The level of perceived burden has been correlated with higher risks of depression and lower quality of life for caregivers (Aronson, 1997).

Caregiver – Caring refers to the act of nurturing, providing, or attending to someone who is in need of such services. Caregiving can best be described as the service of providing informal, unpaid services to family members or friends who have physical, psychological, or developmental needs (Neely-Barnes & Dia, 2016).

Intellectual and Developmental Disability (IDD) – The term Intellectual disability/developmental disability means a severe, chronic disability of an individual that is attributable to mental or physical impairment or a combination of mental and physical impairment. The American Association on Intellectual and Developmental Disabilities (2013) classifies IDD as mild, moderate, severe, and profound. The following provides an explanation of each classification:

Mild: The person requires assistance with activities such as transportation, grocery shopping, or financial management.

Moderate: The person requires assistance with personal care, eating, dressing, or hygiene, and usually requires ongoing support and assistance.

Severe: The person requires support with all activities of daily living, including meals, dressing, bathing, and elimination, therefore requiring supervision at all times.

Profound: The person is dependent on others for all aspects of daily physical care, health, and safety, although the individual may have some measure of participation in activities dependent on any physical impairments (American Association on Intellectual and Developmental Disabilities, 2013).

Children with Disability – Any child 3-18 years of age who is living with a medically diagnosed physical or mental impairment and is thus called a child living with a disability because the impairments result in functional limitations (American Association on Intellectual and Developmental Disabilities, 2013).

Parents - For the purposes of this study, the parent is defined as living in Jamaica and caring for a child diagnosed with an IDD. Additionally, in this study, the subjects may include guardians such as grandparents, who are involved in the care of a child diagnosed with an IDD and living within the same household.

School-Aged Children - For this research purpose, school-aged children in Jamaica are defined as 3-18 years old.

Description of Jamaica and the Culture

Jamaica is an island country situated in the Caribbean Sea, comprising the third-largest island of the Greater Antilles. It is the fifth-largest island country in the Caribbean. Jamaica has

enjoyed independence since 1962 and possesses a two-party political system and a democratic government developed on the Westminster model. The State Department of the United States (2012) reported that Jamaica is a country of around 2.8 million, with just a little over half of the population living in urban areas, approximately 670,000 in the capital of Kingston alone.

As a member of the British Commonwealth, the culture of Jamaica has been deeply influenced by British occupation for over 300 years. The large majority of the population consists of Afro-Caribbeans with small minorities of Europeans, Chinese, East Indian, and Lebanese people accompanied by much inter-racial and inter-ethnic mixing. English is primarily spoken throughout its tropical and mountainous terrain, although a great many continue to speak Jamaican Patois or Creole (Thorburn, 2008).

The indigenous Tainos in Jamaica never established their culture because they were largely wiped out by a disease that was introduced by Spanish settlers. There is great diversity in reported religious beliefs including those of Anglican, Roman Catholic, Baptist, Church of God, Seventh Day Adventist, Pentecostal, United Church, Methodist, Jehovah's Witnesses, Moravian, Brethren, Rastafarian, Muslims, Hindu, Jews, and Bahai members of the Church of God. Jamaica is mainly a Christian country holding the record in the Guinness Book of Records as having the most churches per capita mile (Thorburn, 2008).

While language, laws, and customs in Jamaica are shaped to a great extent by Great Britain's 300 year-long occupations, it is reggae, a distinctively syncopated style of often highly political Jamaican music, that most clearly defines the culture of the island and its people. Reggae is a music form that "emerged from traditional indigenous Jamaican music with African and Black-American roots and was popularized in the twentieth century by the singer Bob Marley and others. The African influence led to the development of Rastafarianism, both a

culture and religion” (Thorburn, 2008, p. 125).

Attitudes toward persons with disabilities remain negative in Jamaica although attitudes have improved over the last 20 years according to the Planning Institute of Jamaica (2009). There are still legal exclusions negatively impacting children and adults with cognitive or intellectual disabilities, although there are several laws that are designed to protect such Jamaicans. Culture influences how parents raise their children and how they may be affected by raising a child with IDD (Marsack-Topolewski & Church, 2019).

Theoretical Framework

The theoretical framework for this study is Madeline Leininger’s Culture Care Diversity and Universality Theory. This theory was chosen, culture is a significant influence in Jamaican life and influences parents’ beliefs and how they raise their children. The theory is predicated on the premise that culturally congruent care is essential for the promotion of health and well-being of cultures (Leininger & McFarland, 2002). According to Leininger, a meaningful and satisfactory fit of culture care beliefs, values, and practices between healthcare providers and care recipients is needed to preserve, maintain, or change care practices for the benefit and satisfaction of clients (Leininger, 1991, as cited by Wenger, 1991, p. 97).

Method

This study followed the grounded theory methodology identified by Strauss and Corbin (1998). Grounded theory as originally developed by Glaser and Strauss (1967) refers to a qualitative research effort that is designed to generate, identify or discover a theory. It is therefore a methodology of analysis involving the systematic collection of data that is sufficient to generate an inductive theory about a substantive area (Strauss, 2017).

Study participants were parents of school-aged children who have been identified as

having IDD. Using purposive sampling, a series of interviews with 21 participants consisting of parents of children diagnosed with IDD was obtained. The interview method as described by Corbin & Strauss (1996) was followed to provide an opportunity to identify the experiences, feelings, and attitudes of individuals who are confronted with a specific task or challenge. It allows for the development of a theory of how culture care beliefs, values, and practices impact the target population of Jamaican parents of children with IDD.

Significance of the Study to Nursing

Leininger and McFarland (2002) emphasized the importance of understanding how health and well-being, as well as illness or disability, are constructed in a culture. Without that understanding, it is all but impossible to provide the kind of potentially successful care that is needed by patients and their caregivers. Since information is limited about adequate services or how those services are perceived by caregivers in Jamaica, the present study offered a unique opportunity to inform nurses and other medical caregivers as to the central issues that need to be addressed in providing support to families where a child with IDD is present.

Samms-Vaughan (2019), a professor of child health, child development, and behavior at the University of the West Indies in Jamaica, told the story of a young Jamaican boy that illustrated the challenges of parents of children with disabilities and the children themselves. DJ was very slow in comparison to his sisters and others, including males of his age, with respect to developing coordinated speech patterns. His mother attempted multiple times to have him assessed and to gain access to preschool programming. She became frustrated in her attempts to obtain an impartial, comprehensive assessment of her child's speech disabilities, leading to substantial delays in receiving services that would improve his communicative abilities. As Samms-Vaughan (2019) has noted, professional healthcare givers need to be educated and

informed more thoroughly about the manifestations of various forms of IDD to ensure that early intervention is provided.

Listening properly to parents who express their concerns about a child's development is critical to nursing within the theoretical framework of Leininger's Culture Care Diversity and Universality Theory (Leininger & McFarland, 2002). It is hoped that the findings in this study will help to inform Jamaican healthcare providers and lead to more positive outcomes for affected parents and their children.

The Grounded Theory Approach

The qualitative method used in the study sought out participants capable of describing their own experiences. The participants described in their own words their personal understanding of what it was like to raise their child with IDD. Grounded theory is an approach for developing theory that is literally grounded in data that has been systematically gathered and analyzed (Corbin & Strauss, 1996). Corbin and Strauss (1996) emphasized two key points: 1) the foundational role in any qualitative research of participants' personal understandings of their social environment, and 2) the importance of flexibility or the need for researchers to creatively tailor the approach to their own research settings and interests. There is, therefore, no mechanistic adherence to a pre-set methodological formula (Corbin & Strauss, 1996).

A study that uses grounded theory, such as the present study, begins with a question that leads to the collection of qualitative data and uses inductive reasoning rather than the postulation of a hypothesis. Researchers review the data that they have collected and then identify and code repeated ideas, themes, concepts, or elements that reflect the data. After data is coded, it becomes possible for the researcher to group codes into concepts and into broader categories, which may become the basis of a new theory (Corbin & Strauss, 1996).

In the traditional model of research, hypotheses are proposed to best test the validity of a specific theory (Allan, 2003). This is not the case when grounded theoretical research is undertaken. Grounded theory, as Corbin and Strauss (1996) have commented, offers ecological validity in that it represents real-world settings. It provides for novelty because findings are not linked to any preexisting theory. It is parsimonious in that it provides both practical and simple explanations about complex phenomena by converting them into abstract constructs and then hypothesizing the relationships that might exist between such concepts.

The proposed study used what Corbin and Strauss (1998) identified as axial coding, along with open and substantive coding that is then subjected to selective coding. This differs from the method that was proposed by Glaser (1996) who rejected the idea of recording interviews. Glaser (1996) argued that the method is not limited to the realm of qualitative research and emphasized an abstract conceptualization of time, place, and people. The difference between the methods of Glaser (1996) and Corbin and Strauss (1996) is that has occurred in this study, the researcher employed a well-defined coding paradigm and looked systematically for causal conditions, phenomena, context, and consequences in the data. Conducting a literature review prior to undertaking such a study provided an opportunity to anticipate the kinds of concepts that are likely to emerge (Corbin & Strauss, 1996).

Summary

This introductory chapter serves to delineate the purpose and background of the study of how Jamaican parents of children diagnosed with IDD deal with the various burdens and stresses they inevitably face. The focus of this study was on parents raising children with IDD living in Jamaica. It also included some grandparents and guardians who are living within the same household and are known to be caregivers of the children with IDD. The chapter demonstrates

that there are various definitions of disability used in Jamaica, but as the Planning Institute of Jamaica (2009, p. 6) has noted, the Jamaican government defines a *disability* as “any restriction or lack of ability to perform an activity in the manner or the range considered normal for a human being. Such restriction or lack of ability must be a result of impairment.”

The theoretical framework of Leininger’s (Leininger & McFarland, 2002) theory of nursing in which culture and care are inextricably linked offered a guiding background to this study. The significance of the study to nursing is highlighted, key terms are defined, and a broad overview of the qualitative methodology involving grounded theory is presented. Chapter 2 of this study offers a review of the literature covering many of the issues introduced herein. Chapter 3 focuses on the explication of the research questions, the purpose of the study, methodology, and the research approach, as well as data collection and analysis. Chapter 4 provides the research findings. Chapter 5 concludes with a supplementary literature review in relation to the study findings, study implications, limitations, and significance.

Chapter 2: Review of the Literature

The literature review explores a variety of topics, including the incidence of disability in Jamaica, programs for children with disabling conditions in Jamaica, the nature of caregiver burden, and those that are specific to parents. Recent scholarly and governmental studies that focused on various aspects of these issues were examined. They depict the nature and the extent of the problem of IDD in Jamaica and the impact on parents in particular.

As Mann (2013) has pointed out in a dissertation on the experiences of mothers of children with an autism spectrum disorder or pervasive developmental disorders, much of the literature has been conducted from a Western perspective. Mann described parental concerns for the child's development, the diagnostic process, and their daily living experiences.

A review of the literature identified limited research on the experiences of raising a child with IDD due to the widespread poverty and a lack of access to modern physical and mental health diagnostic and treatment programs. Consequently, there is much to be gained from studying parents living in that culture to understand and bring awareness to parents caring for children with an IDD.

Incidence of Disability in Jamaica

Research suggests that as many as 200,000 individuals of all ages in Jamaica live with a disability. Therefore, children are at an increased disadvantage in that educational services for special needs students are severely limited as are medical, social, and psychological services (World Bank, 2016). Children with disabilities represent about 6% of the national population and comprise one of the most vulnerable groups in the country. Jamaica passed the Disability Act in 2014 to promote and protect the rights of this population, including programs

that target minor children and their families (World Bank, 2016). Despite the 2014 Act, many children are without adequate educational, medical, and mental health services.

To identify the incidence of IDD in Jamaica, Thorburn in 2008 stated that there were only three comprehensive studies of the prevalence of childhood disability in Jamaica in the past 25 years. The problem identified by Thorburn (2008) and later by Mann (2013) is that the focus on IDD itself has been incorporated into studies of disabilities of all kinds and individuals of all ages. The Jamaican Council for Persons with Disabilities has estimated that there are about one million Jamaicans of various ages who are affected by at least one disability, comprising between 15% and 17% of the country's population (World Bank, 2016).

The Jamaica Information Service (2007) indicated that the wide variety of cognitively and intellectually disabling conditions, unfortunately, complicates the development of easily accessible services for members of this population. Particularly underserved are children with IDD impacting cognitive, language, and fine and gross motor skills. What this suggests is that for many Jamaican parents with children experiencing developmental disabilities, acquiring an appropriate diagnosis and subsequently adequate services and interventions are challenging at best (Wilson-Harris, 2016).

Policy

Policy positions that might affect persons with disabilities are included in the Jamaican Constitution, the National Policy on Disability, and various specific legal provisions. The Jamaican Constitution guarantees certain basic rights for all persons in society, although it does not specifically mention persons with disabilities.

The Planning Institute of Jamaica that was mandated to spearhead the development of the National Development Plan, Vision 2030, stated that in 1999, Parliament convened a committee

to make recommendations on the amendment of the Jamaican Constitution. The National Disabilities Act was passed in the Jamaica Senate in October 2014, finally translating into law the equalization of the rights and opportunities of PWDs in Jamaica. In general, the National Disabilities Act of 2014 provides clear guidelines on the protection of the rights and interests of PWDs in the following areas: protection from discrimination, education, and training, employment, participation in political office and public life, healthcare, access to premises and housing, and public passenger vehicles (Jamaica Council for Persons with Disabilities, 2014). This policy provides guidelines for cooperation between government and civil society in addressing the equalization of opportunities for persons with disabilities.

The Jamaican Council for Persons with Disabilities continues to work toward eliminating ignorance, stigma, and negative attitudes toward PWDs and their families. This research study confirmed the need for public awareness campaigns that would help to educate the public on the rights of PWDs as well as providing factual information on the different types of disabilities.

In addition to the National Policy for Persons with Disabilities, there are several laws that protect people with disabilities. For example, persons with disabilities are recognized and protected under a social protection system. In 1992, income tax concessions were introduced for persons with disabilities. However, few people are able to benefit due to the fact that many are unemployed or fall below the income tax threshold. Additional provisions include education policies, health policies, and reduced bus fares. In cases of violations of their rights, the primary mechanisms for recourse for persons with disabilities are civil lawsuits, criminal prosecutions, and intervention from an independent human rights organization (UNICEF, 2018).

Programs for Children

Children and adults coping with disabling conditions in Jamaica face negative attitudes and prejudices about their capabilities, which often leads to social isolation. For children, it may mean that school is not an option or, alternatively, that school is even more challenging than it would otherwise be. Efforts to improve outreach to families of minor children coping with disabilities include programs fostering stimulation in early childhood and preschool years. However, the funding in Jamaica needed to expand such services (especially in rural areas) is limited at best (World Bank, 2016).

Many of the existing programs targeting children with disabilities and their families are managed under the aegis of the Jamaican Child Protection and Family Services Agency (CPFSA). As of 2019, calls were increasing for early screening of children believed to be at risk for developing or currently exhibiting signs of a disabling condition (Jamaica Observer, 2021). The Nathan Ebanks Foundation, a Jamaican philanthropic organization that has partnered with CPFSA, has taken a lead role in bringing together members of the disabled community and key service providers to develop more effective strategies for meeting parental and child needs. Of significance is an effort designed to train caretakers in assisting children with special needs and also educating the parents. The Ebanks Foundation partners hold an annual Family Expo and Special Needs Resource Fair to bring together members of the disabled community and key service providers (Jamaica Observer, 2021).

Since 1975, the Jamaican Ministry of Labor and Social Security has maintained the Early Stimulation Program (ESP) that addresses the needs of children with developmental disabilities (Jamaica Information Service, 2007). This program offers screening and diagnostic services, beginning with birth and continuing through early elementary school years, that are designed to

assist parents in identifying the existence of a disabling condition and then accessing needed services to facilitate optimum child development. Early stimulation programming in local schools is one beneficial option that, unfortunately, is not universally available in the country. Some local health centers also offer such diagnostic and intervention services (Jamaica Information Service, 2007; Nathan Ebanks Foundation, 2019b).

The role of the Nathan Ebanks Foundation (2019a) in assessing and then serving children with IDD and their families appears to be critical. This organization offers educational programs for caregivers as well as for parents and disabled children. The organization assists in both service delivery and the education of stakeholders. As Morris (2019) commented, the engagement of private sector groups like this in the service delivery area is critical in a country where government resources are limited. Jamaica is the beneficiary of assistance in terms of providing services, including assessment of children with IDD from the World Bank as well as other countries such as Japan. They offer to fund the provision of needed medical equipment and assistive devices for special needs children (e.g., wheelchairs, walkers, hearing aids, prosthetics, and computers). Such equipment is often beyond the financial reach of many Jamaican parents. Morris (2019) noted that the Jamaican Early Stimulation Program is perhaps the primary mechanism used to address the needs of this Jamaican population. Assistance from philanthropies, organizations like World Bank, and country donors are crucial to the effort. Information obtained from this research study will aid in understanding why parents may or may not seek out these services that are important for service providers. Parents' views of caregiving play a role in their parenting behaviors and search for services.

The Ebanks Foundation (2019b) is committed to “ensuring that all children with disabilities and special needs in Jamaica receive equal access, necessary resources and the

opportunity to realize their full potential” (p. 1). The organization has taken a leading role in establishing local and international volunteer service programs that focus on advocacy, public education, training/capacity development, and rehabilitation support. Services are provided to parents, caregivers, children, policymakers, and teachers as well as agency staff that offer direct care. Using multiple tools, including the internet, social media, face-to-face workshops, and classes, the Foundation serves thousands of individuals annually.

Also instrumental in addressing the issues of special needs children and their families are the National Child Development Agency and the Office of the Children’s Registry. The 2004 Child Care and Protective Act established these professional units within the government tasked with assessing the needs of children with disabilities or who were at risk for developing such conditions and establishing policies and programs to meet those needs (Protecting Jamaica’s Children, 2017). Information obtained in this research may offer insights into what services parents seek or do not seek for support.

Research by Mann (2013) examined the experiences of mothers caring for children with autism, which is one of the conditions common in Jamaican children and one of the needs that is seen as inadequately met. Mann found that children with a diagnosis on the autism spectrum are among the most frequently seen special needs children in Jamaica and among the groups least well served. Poor parental understanding of Autism Spectrum disorder symptoms and risk status, lack of early diagnosis, inadequate local services for preschoolers and early elementary students, and challenges in accessing those available services were identified as contributing factors by Mann (2013). Similar comments about children diagnosed with cerebral palsy (Nathan Ebanks Foundation, 2019a), as well as children diagnosed with an intellectual disability or Downs syndrome (Jamaica Downs Syndrome Foundation, 2019) have also been made.

Caregiver Burden

Maternal caregiver burden, a subjective state reflecting the individual caregiver's perceptions, is a widely accepted feature of many caregiving studies that measure the effects of caregiver stressors and emotional symptoms. Thorburn (2008) pointed out that part of the caregiving burden experienced largely by Jamaican mothers of children with IDD involves homeschooling because there are relatively limited special educational programs available to such students, particularly in rural areas. Wilson-Harris (2016) agreed and indicated that a factor contributing to maternal caregiving burden is the issue of the cost of such services.

Wilson-Harris (2016) provided an example of one mother who attempted to receive assistance through the Early Stimulation Program and was told that her child could not be fully assessed for several months due to a long waiting list. Consequently, this particular mother ultimately took out a \$10,000 loan to pay for the services of a developmental pediatrician but found that it was beyond her financial ability to pay for the services of needed speech and behavioral therapists. A major burden placed on parents of children with IDD is accessing affordable services including diagnostic services as well as treatment. This adds to the challenges that confront caregiving parents who also may find that they need to cope with providing for other children in the family and acting as wage earners (Mann, 2013).

Stigma and Social Isolation

Caring for a child with a disability brings multiple challenges to parents, such as additional financial burdens for treating their child's condition, dealing with the child's problematic behavior, and social stigma. It has been noted that stigma is quite prevalent in the community against disabilities, so children with disabilities may not have the courage or confidence to play with other non-disabled children. A qualitative study by Gill and

Liamputtong (2011) identified that mothers felt stigmatized in the way others viewed both them and their children because of their children's appearance and unusual behaviors.

The psychological grief associated with social exclusion can serve as an intense form of punishment (Maner, DeWall, Baumeister, & Schaller, 2007). Research has identified that parents who felt stigmatized had feelings of isolation stemming from society's lack of understanding and had felt as though they were in a world of their own (Woodgate, Ateah, & Secco, 2008). Furthermore, Woodgate et al. (2008) found that after parents had educated themselves about their child's condition, educating others was a means to cope with the stigma.

Parental Stressors

Being a parent can be a very rewarding and joyful experience. However, a parent can also have its share of stress. Raising a child with a developmental disability can inflict added stress on parents from causes related to finances as well as physical and emotional issues. These added stressors can also have an impact on life events, such as childhood illness, marital decomposition, or parental unemployment. Cumulative factors of societal, community and environmental conditions may also play a role. Research has shown that parents of children with developmental disabilities may experience higher levels of stress and depression than other parents and disruption to the family unit is likely to occur (Benson, 2006; Benson & Karlof, 2009; Dabrowska & Pisula, 2010; Feldman, Hayes, Kumar, et al., 2007). According to Kupferberg, Bicks & Hasler (2016), depression is associated with a range of negative effects, including poorer physical health, lack of self-care, and limited social functioning. Plant and Sanders (2007) found some of the variations in parental stress were associated with the caregiving responsibilities related to the heterogeneity of the child's disability, the unique profile of their skills, and the child's behavioral challenges.

Deater-Deckard (2004) defined parenting stress as a set of processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood. Chronic stress could negatively influence parents' health while also impacting their ability to meet their child's needs. According to Duncan, Coatsworth and Greenberg, (2009) the parents' own skills and capacities for regulating their thoughts and emotions are critical to their parenting stress level and coping strategies when faced with stressors in the caregiving role.

Studies conducted outside of Jamaica may or may not directly be applicable to this study's target population of parents raising children with IDD in Jamaica. The focus of this study was to understand how parents perceive and react to their personal stressors.

Resilience

According to the American Psychological Association, resilience is defined as the process of adapting well in the face of trauma or tragedy, threats, or other significant sources of stress (Southwick, Bonanno, Masten, et al., 2014). Parents are resilient when they are able to call forth their inner strength to proactively meet personal challenges, and those in relation to their child manage adversities and thrive given the unique characteristics and circumstances of their family. Some stressors parents face cannot be easily resolved. For example, parents cannot resolve their child's IDD. The Center for the Study of Social Policy (2018) indicates that parents are more likely to achieve healthy, favorable outcomes if they are resilient. Therefore, parental resilience is a process that all parents need to effectively manage stressful situations and help ensure they and their families are on a trajectory toward healthy, positive outcomes. This study can identify how parents describe their personal experiences and manage stressful situations.

Summary

This chapter summarized the literature on IDD in Jamaica. Due to the relative poverty and scarcity of adequate resources in Jamaica, the burden of caring for a special needs child may be challenging for Jamaican parents. The best efforts of the public and private sectors appear, on balance, to be moving in the right direction, but more research is needed on how parents of school-aged children with developmental disabilities experience raising a special needs child. The problem they face and the services they need are issues of caregiver burden that can offer insights in terms of programming and access to high-quality, affordable services throughout the country. The stigma of IDD and associated discriminatory barriers to childhood education is critical. How Jamaican parents react to social influences and access support for themselves and their family needs to be better understood. This study focused on the parents' caregiving experience and challenges associated with raising a child with IDD through the school-age years.

Chapter 3: Methodology

This research study utilized the grounded theory methodology developed by Corbin and Strauss (1996). Grounded theory utilizes an inductive approach consisting of a systemic method to determine a theory based on a social phenomenon. A qualitative research design is utilized for an inquiry that requires a deeper understanding of concepts, experiences, phenomena, or culture. Qualitative research allows the researcher to explore the data in-depth and describe a phenomenon. The purpose of this study was to uncover and understand an in-depth analysis of parenting experience and caregiver challenges of parents with children who have IDD who are living in Jamaica. According to Babbie (2020, p. 117), qualitative research involves the “.... construction of social reality and cultural meaning, a focus on interactive processes and events, dealing with few subjects, involving the thematic analysis and the researcher is fully involved.” This researcher investigated the phenomenon of parents raising children with IDD living in Jamaica. The research questions were designed to help the participants express what is significant and important to them.

Research Questions

The main questions that guided the study are two-fold: (1) What is the experience of parents living in Jamaica and caring for a child with an intellectual or developmental disability and (2) How do they describe their needs and challenges to raising their school-age child? The following specific questions and probes were used to guide the study (see Appendix E).

1. What type of disability were you told that your child has?
2. How did you feel when you were told that your child has a developmental disability?
3. Tell me how you and your family have been affected by having a child with a developmental disability.

4. Tell me about your experiences in caring for your school-aged child with a developmental disability. Do you perceive caring for that child as a burden? Please describe?
5. Describe how caregiving affects you emotionally and mentally.
6. How has caregiving for your child with a disability affected your social and family life?
7. Tell me about who or what is helping you in your daily life, with your responsibilities, and with the care of the child?
8. How do you cope as a caregiver for your child with a disability?
9. What resources are available in your community? Do you access any of these resources?
10. What kind of support do you need to help reduce the challenges of caring for your child?
11. What programs would you like to see put in place that will benefit parents of developmentally disabled school-aged children?
12. What should doctors and nurses be aware of so that they are better able to assist parents who are caring for children with a disability?

Methodology in Grounded Theory

This qualitative study used the grounded theory methodology of Corbin and Strauss (1996). Grounded theory is a form of qualitative research originally developed by Glaser and Strauss (1967) for the purpose of constructing theory (Creswell, 2013). The aim of grounded theory is to generate or discover a theory (Glaser & Strauss, 1965). According to Glaser (1992), grounded theory is a methodology of analysis, which starts from the systematic collection of data, to generate an inductive theory about a substantive area. Strauss (1987) indicated that rather than a theory, grounded theory is more of a methodology that is used to discover theories that are embedded in the data and revealed through inductive analysis.

Charmaz (2006) defined a set of systematic inductive methods to perform qualitative research aimed at developing the theory. The methodological process will involve actual data gathered through fieldwork to identify, develop, and integrate concepts and to form a theory.

Grounded theory is an inductive approach that requires the researcher to begin with a completely open mind of what will be found. Inductive reasoning begins with detailed observations of the world, which moves toward more abstract generalizations and ideas (Neuman, 2003). When following an inductive approach, beginning with a topic, a researcher tends to develop empirical generalizations and identify preliminary relationships as he or she progresses through the research. There are no hypotheses at the initial stages of the research, and the researcher is not sure about the type and nature of the research findings until the study is completed. The aim is to generate a theory based on the data. The researcher will become theoretically sensitive by immersing in the data and trying to understand what the participant sees as being significant and important. Concurrent data collection and analysis will allow the researcher to become theoretically sensitive to the data (Neuman, 2003).

The Corbin and Strauss (2014) method offers a systemic process. These processes were followed in this research study. The researcher begins with data collection and analysis, which is a simultaneous process, interpreting concepts as basic units of analysis. Categories then emerge, are developed, and are relevant. Theoretical sampling in grounded theory proceeds until saturation. The analysis uses constant comparisons to make logical connections among the data. Patterns and variations are accounted for during the analysis process. Theoretical memos are fundamental in accomplishing grounded theory. Corbin and Strauss (2014) used a three-stage coding methodology of open coding, axial coding, and selective coding on how to code and structure data. They used the term “open coding,” with the emphasis on conceptualizing and

categorizing the data as predetermined, coming from the data and from the researcher. “Axial coding” is unique to Strauss and Corbin. It is a set of procedures that put data back together in new ways after open coding, by making connections among categories. “Axial coding” is using coding of conditions, context, action, interactions, strategies, and consequences (Strauss & Corbin, 2014).

Glaser and Strauss (1965, 2017) provided some guidance for the evaluation of grounded theory. These underlying aims of the theory are fit, understandability, generalizability, control, and can be summarized as follows:

1. Does the theory fit the substantive area in which it will be used?
2. Will non-professionals concerned with the substantive area understand the theory?
3. Does the theory apply to a wide range of situations in the substantive area?
4. Does the theory allow the user some control over the “structure and process of daily situations as they change through time”?

Symbolic Interactionism

Grounded theory methodology and symbolic interactionism philosophy are not only compatible in their goals, but also in their assumptions. With symbolic interactionism and grounded theory, human beings and shared meanings of reality can be defined only through interaction between and among the researcher and participants in the context of the phenomena of interest. The early theoretical underpinnings of Grounded Theory as described by Glaser and Strauss (1965) suggested that it was theoretically adaptable.

Blumer (1986) described symbolic interactionism as a theory of human life and human conduct, focusing on the various social aspects of human action and interaction. According to Blumer, the way humans respond or react to things depends on the meaning that things have for

them. The meaning that things have for humans comes from their experiences and social interactions with others and their interpretation of the experiences. Grounded theory was appropriate for studying this phenomenon because little is known in this population about the nature of action and interaction in parents raising children with IDD living in Jamaica.

A grounded theory provides the researcher with a theory that accounts for a pattern of behavior that is relevant and problematic for those involved (Glaser, 1967). The basic building blocks for grounded theory are the concepts grounded in the data.

The core concept that was identified in this study was *the challenges they face*. It aligns with Blumer's (1986) theoretical perspective of symbolic interactionism. Blumer's theoretical perspective is a social theory about human behavior and inquiry into human conduct. The meaning of things comes from social interaction with others and the interpretation of others and the interpretation of experiences. Blumer's (1986) theory is built upon the following concepts:

1. Humans act toward things based on the meanings that the things have for them.
2. The meanings of such things are derived from the social interaction that one has with the other.
3. These meanings are refined through an interpretive process used by the person dealing with the things they encounter.

Parents raising children with disabilities living in Jamaica is an interpretive process on how the parents deal with the challenges they encounter in raising their child with IDD. The parents dealt with the challenges based on the meaning the process holds for them. The meaning of the process and the implications of the challenges of raising children with IDD occur over time as the parents make sense of and define their experience and challenges in raising children with IDD. The meaning of their experiences and challenges occurs by examining their interpretation

of their experiences, the decisions they make, and how they dealt with the challenges.

Theoretical Framework

The theoretical framework for this study is Madeline Leininger's Culture Care Diversity and Universality Theory. This theory was chosen, as it appears that culture is a significant influence in Jamaican life and sets the stage for parents' beliefs and how they raise their children. The theory is predicated on the premise that culturally congruent care is essential for the promotion of health and well-being of cultures (Leininger & McFarland, 2002). According to Leininger, a meaningful and satisfactory fit of culture care beliefs, values, and practices between healthcare providers and care recipients is needed in order to preserve, maintain, or change care practices for the benefit and satisfaction of clients (Leininger, 1991, as cited by Wenger, 1991, p. 97).

Researcher Perspective

My personal interest in this topic derives from my experiences interacting with a young family member diagnosed with IDD. It is a subject that I have researched as an undergraduate student in the field of psychology. I was interested in exploring the question of caregiver challenges specific to Jamaica. As a country with limited resources facing many infrastructure problems and needs, particularly in the field of childhood education (McDonald, 2000), Jamaica represented an opportunity to explore an issue that has been given relatively limited attention in the literature.

Bracketing is a technique I followed when conducting this study so as to hold my preconceptions aside and keep them from influencing the data and analysis. Bracketing is a method described by Tufford and Newman (2012) as one used in qualitative research to mitigate the potentially deleterious effects of preconceptions on the part of a researcher that might taint the

research process. Bracketing requires the researcher to differentiate between his or her personal and professional selves, to draw awareness to presuppositions regarding the topic, and then to formulate research questions that address conceptualization of the study itself. Bracketing further requires data collection that focuses on the experiences and perspectives of participants that are examined to identify the emergence of themes and concepts that ultimately give voice to participants' thoughts while imparting the researcher's critical analysis and understanding.

Study Participants

The study design was for participants to be parents of school-aged children who have IDD and are living in Jamaica. Grandparents and guardians who are directly involved in the care of the children and are living in the same household were permitted to be included. The children had to have a developmental or intellectual disability. Disabilities such as spinal and limb disabilities, Down syndrome, epilepsy, autism spectrum disorder, cerebral palsy, and neurological impairment were included. They may also have sensory deprivations, speech or language deficiencies, vision or hearing anomalies, and possible related or overlapping genetic disorders. Parents were asked to speak about raising their children who ranged from 3 to 18 years old. This age range was chosen as school-age represented apparent increased stress and responsibility for parents in a place where resources are quite limited.

Human Subjects Consideration

Institutional Review Board (IRB) approval from Molloy College (see Appendix G) was obtained to conduct this study so that the ethical treatment of subjects was assured. Approval was also obtained from The Jamaica Ministry of Health Ethics Committee (see Appendix H & I). Permission to audiotape the interview and permission to transcribe the data by an outside transcribing agency was obtained. Interviewees were assured that the information they provided

will be kept confidential and no names will be used in the transcription of the interviews and in audio cassettes or computer printouts or field journals. All biographic data will be stored under lock and key by the researcher and only those people who are involved in the research will be able to study the data. Data from each interview were identified only by numbers and pseudonyms. The participant's name was not used when the recording was sent for transcription. In using the snowball strategy, no information was given to any interviewee about referrals and who will be the next to be interviewed. Names and identifying data were not used, in any final written document or publication. Participants were fully informed about the study by the researcher and by written consent.

Informed Consent

A Molloy College IRB Informed Consent Approval Form (see Appendix G) explained the purpose of the study. The semi-structured interview guide was provided to the IRB, with the understanding that the researcher would personally be conducting the interviews. The semi-structured, open-ended interview questions allowed for adequate prompting of the participants. Parents and guardians completed and signed the consent, acknowledging that they were willing to participate in the research study. Informed consent was obtained from the participants prior to the researcher conducting any interviews. The consent was written at an eighth-grade reading level. The consent form with a written explanation of the study was provided for the parents that included the purpose of the study, the voluntary nature of the study and the participant's right to withdraw at any time, the risks and benefits of participation, Molloy College's listing as the institution with which the principal investigator was affiliated, and measures to provide for confidentiality. If the participants had questions or concerns, they were also advised to contact The Jamaica Ministry of Health Ethics Committee. A contact name and number were provided.

Participation in the study was entirely voluntary and participants were given the opportunity to ask questions prior to, during, and following the interview. The participants gave consent to be interviewed, which included the ability for the participant to withdraw from the study at any time. The name and telephone number of the researcher was listed on the consent. The intent of the study and possible future publication was explained in the consent. The participants could contact the researcher for the results of the completed study. No names or identifying characteristics were used in the study, the interviews, or during the analysis of the data.

Potential Risks

There were no research-related risks or psychological discomforts anticipated in this study. However, if the participants were to feel tired from talking or emailing for 1-2 hours, they knew they would be able to stop the discussion at any time without consequences or reschedule the interview. No one expressed the need to stop or reschedule the interview. Safeguards were put in place to protect the confidentiality of all information. Only the researcher knows the identity of the participants who agreed to participate in this study. Pseudonyms were given to all participants and were maintained in the transcripts.

Potential Benefits

There were no direct benefits to the participants. However, the potential benefits of the study involve the contribution that the findings provide in addressing and filling the current gap in the nursing research literature and nursing knowledge on the subject of parents raising children with IDD living in Jamaica. This study may facilitate the education of Jamaican healthcare providers, members of society, and lead to more positive outcomes for affected parents and their children.

Inclusion/Exclusion Criteria

Participants needed to be parents of school-aged children of ages 3 to 18 years old who had been diagnosed with an IDD. The diagnosis must have been present for a minimum of one year to give parents sufficient time to reflect on their situation. The parents and child had to be living within the same household within Jamaica. They had to be fluent in the English language and/or the Jamaican dialect of Patois. The researcher is fluent in English and Patois. Anyone interested in participating but who did not meet inclusion criteria was excluded. All interested individuals met the criteria. Guardians or grandparent caregivers living in the same household and directly involved in the care of the child with IDD were also included in the study.

Recruitment

After approval from Molloy College IRB and The Ministry of Health Ethics Committee, a flyer with the study information and the researcher's contact information (see Appendix A) was provided to family members, friends, and colleagues who referred potential participants to the researcher. The distribution of fliers was successful in obtaining participants. Although the criteria were clearly outlined on the flyer, several parents who had children over 18 years old with IDD expressed interest in participating. The researcher declined their participation in the study. Participants were selected through the researcher's family members and word of mouth. This type of recruitment allowed for snowball sampling to naturally occur. Additionally, participating parents and guardians helped to recruit additional interested study participants. The researcher conducted an initial screening interview via telephone for the eligibility of interested participants (see Appendix B). The telephone screening enabled the researcher to discuss the interview process to determine the interest and eligibility of potential participants. If a participant showed interest in the study, the study process was explained and an interview was scheduled.

Participants were interviewed by telephone and one participant requested to be interviewed by Zoom. Participants were given a gift card worth \$25 (US dollars) for their time and participation in the study.

Sampling Methods

For the purpose of planning a qualitative study using a grounded theory approach, a purposive sample was obtained through recruitment and snowballing. Charmaz (2006) suggested 20-30 participants develop a well-saturated theory. For this study, a total of 21 participants were interviewed. Data saturation was reached at 16 but interviewing continued according to methods to confirm the theory.

Purposive Sampling

Purposive sampling, also known as judgment, selective, or subjective sampling, is a sampling technique in which the researcher relies on his or her own judgment when choosing members of a population to participate in the study. Purposive sampling is a non-probability sampling method. It occurs when those selected for the sample are chosen by the judgment of the researcher. Researchers may find that they can obtain a representative sample by using sound judgment (Black, 2019).

This sampling method was chosen for this study because it offered promise with respect to gathering real experiences, emotions, and attitudes from parents faced with caring for a child with IDD living in Jamaica. As Babbie (2020) indicated, unlike random sampling studies, that deliberately include a diverse cross-section of ages, backgrounds, and cultures, the idea behind purposive sampling is to concentrate on people with particular characteristics who will better be able to assist with the relevant research.

Snowball Sampling

Snowball sampling will emerge with referrals from initial participants to generate additional participants (Corbin & Struass, 1996). This type of sampling generates referrals from original participants who knew additional people who met the study criteria and could be potential participants (Creswell, 1998). Three participants were referred by other participants. Snowball sampling was useful in this study, as the participants who were referred were scattered geographically and not found in one specific area.

Theoretical Sampling

Theoretical sampling is a process by which the data is collected to generate a theory. The researcher will collect, code, and analyze the data and then decide what further data to collect in order to develop a theory as it emerges. An advantage of theoretical sampling is that it strengthens the rigor of the study and provides a structure to data collection as well as data analysis. Coyne (1997) stated that theoretical sampling is very flexible, as the researcher can make shifts in plans at any time in the research process so that the data gathered reflects what is occurring in the field.

Sample Size

According to Polit and Beck (2008), grounded theory research is done using a sample size that may range from 20 to 30 using a theoretical sampling method. In this research study, the researcher anticipated that approximately 20 participants or more would be needed until data saturation took place. However, data saturation occurred after 16 interviews; 5 more interviews were conducted for confirmation of the theoretical schema.

Interview Setting

Interviews were scheduled to accommodate the needs of the participants. An interview (one to two) and a follow-up interview as needed were conducted in a mutually agreed-upon

venue that would allow for privacy and confidentiality during the interview process. Telephone interviews were conducted at a time convenient for the participants. Internet-based interviews were offered to the participants by email and live video conferencing tools such as Skype, Facetime, and Zoom. The participants all chose to be interviewed by telephone except for one who requested to be interviewed by Zoom.

Each participant was asked to engage in one to two initial interviews, as needed, to share their story. However, only one initial interview was found to be necessary by both the researcher and the participants. A follow-up interview by telephone was requested of all the participants to revisit the recalled aspects of their experience. The participants could provide additional information or correct any errors and review the researcher's assessment of their information. This provided the opportunity to assure the trustworthiness of the data. A total of six parents and guardians participated in the follow-up interviews.

All participants were also given the opportunity to review their verbatim transcripts, but none desired to do this. However, all expressed an interest in the published dissertation. The researcher also used field notes and memos that enhanced recall of nonverbal or informal communication regarding the experience, and these added to the researcher's perspective of what transpired during each interview.

Data Collection Procedures

Consent, which included the purpose of the study, was obtained from the participants by email or postal service, following Molloy College IRB regulations. (see Appendix C). The participants were informed that the interview was voluntary and that they have the right to withdraw at any time. Participants were assured that the information provided will be kept confidential and no names will be used in the interview recordings. The risks and benefits of the

study were discussed with the participants. The contact information of the investigator was provided for questions and concerns. In this study, the investigator collected the data by email and audio recording of telephone and live internet interviews. Demographic data were collected over the telephone by the researcher after consent had been obtained. This included the participants' characteristics of gender, age, marital status, and education, in addition to family and caregiving details (see Appendix D). Notes were taken during the interview process to maintain an accurate record of the interview data. Field notes were maintained of observations and initial researcher thoughts about the interviews. Open-ended questions were used to engage the participants in a meaningful way about their caregiving experiences. The interview questions were developed to help facilitate responses to enrich the data (see Appendix E). Interviews included descriptive, narrative, structural, evaluative, comparative, and circular questions as well as prompts and probes. Semi-structured, in-depth interviews are considered to provide a wealth of data (Smith & Shinebourne, 2012).

Memos

Memos can be analytical and conceptual rather than descriptive, and can be code notes, theoretical notes, or operational notes; a single memo can have elements of all three (Corbin & Strass, 1996). During the interview, the researcher wrote memos that linked coding and theory development. The memo process (operational and theoretical) allowed the researcher to write down thoughts regarding the data at the time of collection and aid in developing an audit trail. Theoretical memos represent the researcher's ongoing record of how the theory was developing. Operational memos recorded the methodological decisions and problems encountered during the interview process (Lincoln & Guba, 1985). Memos create an important extra level of narrative: an interface between the participant's data, the researcher's interpretation, and wider theory.

Field Notes

Field notes were maintained by the researcher. They are intended to be read as evidence that gives meaning and aids in the understanding of the phenomenon. The field notes and memos contained supplemental information about the interview process and emerging theoretical insights and were included in the data set (Corbin & Strauss, 1996). Field notes were preserved with confidentiality, as the interview data and transcribed interviews were securely locked in a file drawer to which only the researcher had access.

Data Management

Only the researcher knew the identity of the parents and guardians who agreed to participate in the study. Pseudonyms were given to all participants and were contained in the transcript. The names of participants, transcripts, and all related information were maintained in a securely locked file drawer to which only the researcher has access. Hard copies of the consents are stored in the investigator's double-locked files. Computer-based data are password protected by the investigator. The one Zoom audio file was transcribed into a computer-based file and the original source was deleted. Telephone recordings were transcribed to a computer file. At the completion of this study and any potential publications or presentations, all study computer records will be printed and also transferred to a memory flash drive and deleted from computer use. The printed record copies, along with backup flash drives, can then be safely stored along with the consent and interview recordings for the period of years as required by Molloy College IRB.

Data Analysis

A characteristic of grounded theory is concurrent data generation/collection and analysis. The recorded data have been subjected to close, line-by-line analysis of the experiential claims,

concerns, and understandings of each participant (Smith & Shinebourne, 2012). The goal of data analysis is to describe, explain, or predict a phenomenon by conceptualizing beyond the individual participants to represent a group experience. Analysis of the data was used to develop concepts and describe themes common to the participants. Corbin and Strauss (2014) refer to the process of analyzing data as coding. Insights gained from this process helped to develop a theory.

Theoretical sampling and theoretical comparison allowed the researcher to complete ongoing data analysis, providing for the identification of themes or the potential direction of the data. The semi-structured, open-ended interview questions were used as a guide for collecting information. The participants elaborated with minimal prompting and the use of probe questions.

Data Transcription

A digital audio recorder was used during the interviews. All data obtained after the interviews were transcribed by a professional transcription agency that assured confidentiality. Numbers and pseudonyms were associated with each audiotape and transcript. After the transcription of the digital audiotapes was completed, the researcher reviewed the transcriptions while listening to the audiotape to clarify any parts of the interview that may have been unclear to the transcriptionist (Penrod, Dellasega, Strang, et al., 1998). Transcripts and audiotapes are stored in the researcher's locked file drawer. Data on the researcher's computer are double password protected. Data will be retained according to IRB protocol.

Coding of the Data

Coding involves three levels of analyses: (a) open coding, (b) axial coding, and (c) selective coding, to gather a complete picture of the information obtained during the data collection process (Corbin & Strauss, 2014). Coding is the crucial link between collecting or generating data and developing a theory that explains the data. According to Charmaz (2012,

p.5), codes rely on the interaction between researchers and their data and consist of short labels that the researcher constructs while interacting with the data.

When coding the interviews, in order to become familiar with the data, the researcher read the interviews more than once to reflect on what was experienced during the interviews and listened to the recorded audio. After open coding, connections were made between themes using axial coding. The theory was inductively produced from themes grounded in the data consistent with the grounded theory methodology. The core variable was essentially the main theme that explained most of the variation in the data and linked the various data together. It addressed the basic social problem that the participants faced and attempted to explain their challenges.

This researcher followed Corbin and Strauss's (2014) approach and attempted to identify a core category, methodically connecting it to other categories, validating connections and relationships, and then completing categories that needed further refinement and development. Only after the process of integration and refining all the key categories into the selection of a core category did the theory emerge (Corbin & Strauss, 2014).

Constant Comparative Method

Grounded theory is a labor-intensive task that requires the researcher to invest time in the processes of analysis and data collection. The constant comparison method was used by the researcher to develop concepts from the data by coding and analyzing at the same time as described by Taylor, Bogdan and DeVault (1998). This method allowed the researcher to combine systematic data collection, coding, and analysis with theoretical sampling in order to generate a theory that is integrated, close to the data, and expressed in a form clear enough for further testing.

The benefit of using this method is that the research began with raw data, and through constant comparisons of that data a substantive theory emerged (Glaser & Strauss, 1967). The incoming data were analyzed with the present data using constant comparative analysis. Study analysis began after the first interview and continued with each sequential interview. After open coding and axial coding, the researcher found a central category that related to all other identified categories by making use of diagrams, theoretical memos, and by reviewing the participants' stories. Using constant comparative analysis, the interview data were reviewed to identify common threads within the reported experience (Glaser & Strauss, 1965).

Filling in Categories

According to Corbin and Strauss (2014), in theory, building the analyst aims for density, which is the identification of salient properties and dimensions in categories. The categories need to have precise variation in identified categories. The ultimate criterion for finalizing the data-gathering process is theoretical saturation, which happens when no further properties and dimensions emerge from the data and much of the possible variations are explained. This researcher followed the theory building as explained by Corbin and Strauss (2014). After the initial data collection and comparative data analysis, the categories and subcategories were identified and linked to a central category. Additional data collection was done to fill in the categories until data saturation occurred and concepts and categories were well defined.

Trimming the Theory

Data trimming is the process of removing or excluding extreme values, or outliers, from a data set. Data trimming is used for a number of reasons and can be accomplished using various approaches. When there is excessive data and some ideas do not fit the theory, Strauss and Corbin (1998) advise dropping them instead of cluttering the theory. If the fit is not correct, that is, if the

abstract does not fit with data, those categories are reevaluated and an additional member-checking strategy is required. In this research study, the researcher evaluated all categories and subcategories that were developed for properties and dimensions and found they clearly fit the theory. Trimming was not necessary for this study.

Strategies to Enhance Scientific Rigor and Trustworthiness

One of the major challenges in qualitative research is establishing trust in the theoretical insights that the researcher proposes to explain or understand. In this study, the trustworthiness or rigor of a study refers to the degree of confidence in data, interpretation, and the methods used to ensure the quality of the study (Polit & Beck, 2008). The researcher established the protocols and procedures for this research study to be worthy of consideration by readers. To develop trustworthiness in qualitative research, Lincoln and Guba (1985) initially presented four criteria: credibility, dependability, confirmability, and transferability. In 1994, Guba and Lincoln (1994) added a fifth criterion:

Credibility

Credibility refers to the truth of data or the participants' views and the interpretation and representation of them by the researcher (Polit & Beck, 2017). Credibility is enhanced by the researcher verifying the research findings with the participants. To support credibility when reporting a qualitative study, the researcher should demonstrate engagement, methods of observation, and audit trails kept through ongoing journal writing and self-memoing as Corbin and Strauss (1996) described. A qualitative study is considered credible if the descriptions of human experience are immediately recognized by individuals that share the same experience. For this research study, interviews with participants were conducted over a three-month period. Each participant interview lasted approximately 1 to 2 hours, generating a total of 546 pages of

transcript data. The researcher conducted follow-up telephone interviews with participants to verify data collection. The follow-up telephone interviews determined if the findings the researcher had discovered were an accurate reflection of the participant's own experience. Follow-up telephone conversations also provided an opportunity for the study participants to validate or correct the information from the researcher's initial interview. It also provided an opportunity for the researcher to increase the depth of the data and attempt to close gaps in the emerging analysis (Morse, Barrett, Mayan, et al., 2002). The researcher used her field notes and memos to enhance the experience and to recall nonverbal and/or informal communication from the participants regarding their experiences. Frequent discussions and debriefing took place between the researcher and the research committee chairperson, before and during data collection and during data analysis. In these debriefing sessions, collaboration occurred while the data were reviewed and discussion transpired regarding any methodological matters, data analysis, dissertation progression trajectory, and any other identified matters to be addressed. In this research study, the researcher kept accurate notes of each concept and category as they emerged in the interviews. The transcription of the recorded interviews also served to establish credibility.

Dependability

Dependability can be achieved when another researcher concurs with the decision trails at each stage of the research process. Dependability refers to the constancy of the data over similar conditions (Polit & Beck, 2012; Tobin & Begley 2004). A study is deemed dependable if the study findings can be replicated with similar participants in similar conditions (Koch, 1994). The detailed descriptions provided in this study would provide such a future replication. The researcher's dissertation committee was available to review the data and analysis to assess its

accuracy. The researcher's dissertation chairperson has reviewed all the participant audio interviews with transcripts and the final analysis of findings. During the research process, the researcher maintained field notes as well as operational and theoretical memos.

Confirmability

The researcher demonstrated confirmability by describing how conclusions and interpretations were established and exemplifying that the findings were derived directly from the data. Confirmability refers to the researcher's ability to demonstrate that the data represent the participants' responses and not the researcher's biases or viewpoints (Polit & Beck, 2012; Tobin & Begley, 2004). This can be exhibited in qualitative research by providing rich quotes from the participants that depict the analysis. In this study, the researcher incorporated multiple direct quotations from participants as a key element in the data analysis process. Dr. Susan Vitale, a method expert in qualitative grounded theory methodology, also conducted confirmability audits by the initial review of the raw data; review of field notes and memos; as well as a review of theoretical themes, categories, and relationship of constructs.

Transferability

A qualitative study has met this criterion if the results have meaning to individuals not involved in the study and readers can associate the results with their own experiences. Transferability refers to the findings that can be applied to other settings or groups (Houghton, Casey, Shaw, & Murphy, 2013; Polit & Beck, 2008). The researcher provided sufficient information on the research context to enable the reader to assess the findings' capability of being fit or transferable. In this study, the researcher accomplished this through rich quotes from the participants, an explanation of the analysis, reference to the literature on the subject, and data validation from the participants.

Authenticity

Authenticity refers to the ability and extent to which the researcher expresses the feelings and emotions of the participants' experiences in a faithful manner (Polit & Beck, 2012). By interpreting data in this descriptive approach, readers can grasp the essence of the experience through the participants' quotes. Sufficient numbers of direct quotations provided by the participants were employed to ensure the accuracy and authenticity of the analysis and the categories developed based on the participants' own expressions.

Summary

This qualitative study used grounded theory methodology, which was appropriate for studying this phenomenon, as there is little known about parents raising children with IDD living in Jamaica. Participants were asked to take part in interviews conducted by the researcher utilizing a researcher-developed, semi-structured interview guide with probes.

The details of how the data was collected, recruitment criteria, IRB approval process, and human subject consideration were outlined in this chapter. Data collection procedures and the process of data analysis and theory development were explained. Inclusion and exclusion criteria for the participants and the research questions and interview guides and probes were outlined. The data analysis process was explained in detail, with methods to ensure the scientific rigor and trustworthiness of this qualitative study.

Chapter 4: Results

The purpose of this grounded theory study was to understand the parental experience and caregiving challenges of raising children who have IDD and are living in Jamaica. An additional goal of the study was to explore how parents' needs evolve over the child's school-age years, in their own words.

The participants of the study involved 17 mothers, 1 father, 2 grandparents, and 1 sister who were raising children who have IDD. In order to allow the researcher to fully understand the phenomenon under study, the experiences and challenges of a parent and guardian were explored through interviews. The ages of the participants at the time of the telephone interview ranged from 26 to 61 years of age. Participants were English speaking, although some participants spoke patois during the interviews. Participants resided in both urban and rural Jamaica.

The group of participants included parents and guardians raising children with an IDD in Jamaica ($n = 21$), a parent who is a mother ($n = 17$), a parent who is a father ($n = 1$), a parent who is a grandmother ($n = 2$), and a guardian sister ($n = 1$). The mean age of parents was 25.3 years and the mean age of the children with an IDD was 5.7 years. The summary of the parent/guardian participants and their pseudonyms, gender, age, child's disability, age, and gender are presented in Table 2.

A summary of demographic data is presented in Table 3. Participants invited to be involved in the study were from various parishes in Jamaica. The participants were raising children with an IDD while living in Jamaica.

Table 2: Participants and Pseudonyms, Parent, Age, Child's Disability, Age and Gender

Participants #	Pseudonym: Parent	Parent	Age of Parent	Child Disability	Age of Child	Gender of Child
1	Rosey	Mother	32	Dandy-Walker Syndrome & Hydrocephalus	4	Male
2	Kay	Mother	27	Down Syndrome	7	Male
3	Shay	Mother	29	Global Developmental Delay	8	Female
4	Joy	Mother	61	Down Syndrome	16	Male
5	Ms. Brown	Mother	45	Speech Impairment & Heart Disease	18	Female
6	Pinky	Mother	26	Spinal Bifida	8	Female
7	George	Father	53	Porencephalic Cyst & Physical	8	Male
8	Simone	Mother	30	Autism Spectrum Disorder	9	Boys
9	June	Mother	28	Cerebral Palsy	3	Girl
10	Wendy	Grandparent	55	Autism Spectrum Disorder	5	Female
11	Mother Hen	Mother	40	Developmental Delay & Intellectual Disability	10	Male
12	Evelyn	Mother	49	Autism Spectrum & Speech Disability	9	Female
13	Sandy	Grandparent	57	Autism Spectrum Disorder & Epilepsy	13	Male
14	Crystal	Sister	26	Deaf & Speech Impairment	10	Male
15	Kiva	Mother	38	Physical Disability	8	Male
16	Brenda	Mother	31	Down Syndrome	11	Female
17	Birdy	Mother	59	Down Syndrome	16	Male
18	Shelly	Mother	38	Cerebral Palsy & Limited Mobility	5	Male
19	Keisha	Mother	43	Dandy Walker Variant, Intellectual, Large Left Arachnoid Cyst	13	Female
20	Molly	Mother	30	Physical Disability	12	Male
21	Pat	Mother	38	Autism Spectrum Disorder	16	Male

Table 3: Summary of the Demographic Data

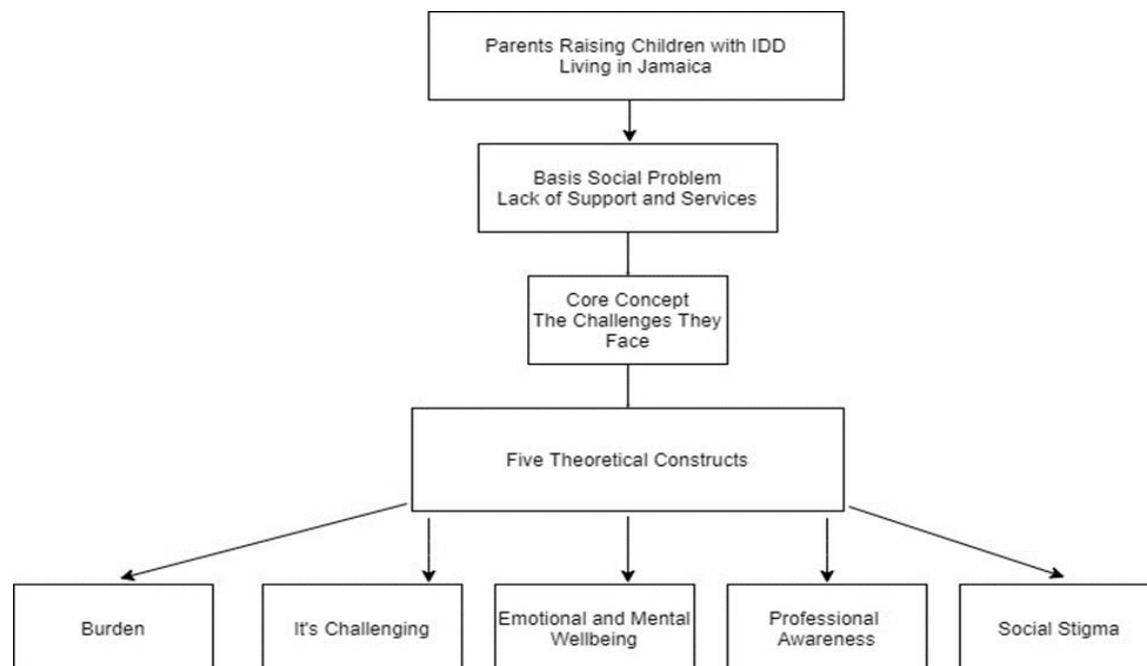
Participants	21
Age	26-61
Parental Status	Mother (17), Father (1), Grandparents (2), Sister (1)
Marital Status	Single (14), Married (6), Divorced (1)
Number of Children	1 Child (4), 2 Children (10), 3 Children (3), 4 Children (2), 7 Children (1)
Age of Dependents	2 Months old – 19 Years old
Age of Child with Disability	3 Years old -18 Years old
Gender of Child with Disability	Male (14) Female (8)
Others Living in the Home	None (9), Grandparents (5), Spouse (5) Aunt (2), Uncle (2), Daughter (2), Son (1), Nephew (3), Niece (1)
Education	Primary (0), Secondary (15) ,Tertiary (5)
Employment Status	Self-Employed (4), Permanently Employed (7), Part-Time Employed (2), Not working Outside the Home (8)
Income	No Income (3), Assistance from Family (4), Sell Goods (1), Raises Chickens (1)
Religion	Christian (12), Church of God (4), Seventh Day Adventist (2), Baptist (1),
Causes of Financial Difficulties.	Medical Bills (8), Transportation (3), Food (3), Loan (1), Personal Items, Rent (2)
I am not Financially Secure	Financial Difficulties (9), COVID-19 (2), Unable to Provide (1), Unable to Purchase Personal Basic Food & Clothing (1)
Support	None (6), Spouse (6), Parents (2), Grandparents (2), Father (2), Siblings (3), Family (7), Friends (4)
Self-Described Ethnicity	African (11), Black (10)
Participant's Health Problems	None (6), Depression (5), Stress (2), Anxiety (1), Diabetes (1), Hypertension (3), Hypotension (1)
Others with Health Concerns and Living Home	None (18), Schizophrenia (1), Visual Impairment (1), Diabetes (1)
Child Disability	Hydrocephalus & Dandy walker Syndrome (1), Down syndrome & Speech (1)

	Autism & Speech Disorder (4), Global Developmental Delay (1), Physical Disability (2), Spinal Bifida (1), Down Syndrome & Visual Impairment (1), Autism Spectrum Disorder (3), Cerebral Palsy (1), Autism & Epilepsy (1), Developmental & Intellectual (1), Cerebral Palsy & Limited Mobility (1), Dandy-Walker Variant, Intellectual, Large Arachnoid Cyst, Deaf & Speech (1)
School Child with Disability Attends	None (12), Primary (6), Private (1), Early Childhood (1), School for the Deaf (1), Special Education (11)
Government Assistance	None (20), Wheelchair from JCPD (1)
Therapy	None (11), Physiotherapy (2), Physical Therapy (4), Occupational & Physical Therapy (1), Speech (1), Speech Behavioral (1), Psychologist (1)
Government Financial Assistance	None (10), Programme of Advancement Through Health and Education (10), Jamaica Council of Persons with Disabilities (1)
Greatest Wish	<ol style="list-style-type: none"> 1. To improve and be able to finance his needs. 2. For him to be able to speak. 3. That my child knows how much I love her and I will always be there anyway I can. 4. To see but something good in life. 5. To be able to speak properly. 6. For her to be able to walk one day and to always be happy and not feel left out. 7. To get an education and be something in life. 8. To lead a normal, healthy life. 9. That she does everything that a normal child her age should be doing. 10. That she achieves her different milestones and developmental stage. 11. To be able to read and write, especially his name. 12. That she may get over her speech disability. 13. For him to read and write. 14. For him to live a fully normal life and be happy. 15. For him to have the best possible. 16. To reach her full potential and to receive assistance in every possible way. 17. For him to be better after two major surgeries. 18. To walk like a normal child and get an education. 19. For him not to have a special need. 20. That one day she may be able to operate as much as possible as a normal child. 21. To be independent.

Basic Psychosocial Problem

The analysis of the interview data identified the *lack of support and services* as the basic social problem. *The challenges they face* was identified as the core concept among the parents and guardian raising children with an IDD in Jamaica. The study participants identified having difficulty accessing government services and getting support for their child with IDD. The study identified five theoretical constructs that the parents and guardians expressed about their experiences and challenges in caring for their child with an IDD (see Figure 1).

Figure 1: Constructs of Parents Raising Children with Intellectual and Developmental Disability Living in Jamaica



Core Concept

The core concept identified through this qualitative research was the challenges they face. This explained the parents' experiences and the many challenges they encounter in raising their child with IDD living in Jamaica.

Description of Data

The purpose of this grounded theory study was to develop a concrete theory that would explain the experiences and challenges of parents caring for children with IDD in Jamaica. Lack of support and services were identified as the basic social problem, and the challenges they face were identified as the core concept of the experiences and challenges of parents raising children with IDD in Jamaica.

Answering the Research Question

The findings that answer the research question are presented in the following sections. First, the conceptualization of the Basic Social Problem, lack of support and services, is explained. Then an outline of the core concept, the challenges they face, is introduced. In the next five sections, the five categories and their related concepts are described. The responses of parents and guardians and their experiences and challenges in caring for their child with an IDD in Jamaica are illustrated and explicated. A list of some commonly used terms and definitions by the Jamaican participants is provided (see Appendix F). A description of the research participants is presented in Table 4.

Table 4: Description of Research Participants

	Pseudonym	Child Disability	Description
1	Rosey	Dandy-Walker Syndrome & Hydrocephalus	Rosey was a 32-year-old single mother who has a 4-year-old son with Dandy-Walker syndrome and hydrocephalus disability. Her highest level of education or training was secondary. She was unemployed and her only support was her mother. She expressed feelings of stress and depression at times. Rosey's greatest wish for her child with a disability was for him to improve and to be able to finance his needs.
2	Kay	Down Syndrome	Kay was a 27-year-old mother of two children, and her 7-year-old son has Down syndrome. Her highest level of education and training was secondary. She was unemployed and her only support was her aunt. Kay expressed that she has hypertension. Kay's greatest wish for her son with a disability was for him to be able to speak.
3	Shay	Global Developmental Delay	Shay was a 29-year-old single mother of one daughter with a global developmental. Her highest level of education and training was tertiary. She was employed part-time and her support is her spouse. Shay's greatest wish for her daughter was for her to know that she loves her and will always be there for her.
4	Joy	Down Syndrome	Joy is a 60-year-old single mother of four children, and her 16-year-old son has Down syndrome. Her highest level of education and training was secondary. She was unemployed and her support was her child's father. Her greatest wish for her son with Down syndrome was to see him become something good in life.
5	Ms. Brown	Speech Impairment & Heart disease	Miss Brown was a 45-year-old married mother of four children, and her 18-year-old daughter has a speech impairment and heart disease. Her highest level of education and training was secondary. She was unemployed, and her support was her spouse and her older children. She expressed that she has diabetes. Miss Brown's greatest wish for her daughter with a disability was to be able to speak properly.
6	Pinky	Spina Bifida	Pinky was a 26-year-old single mother of two, and her 8-year-old daughter has a disability. Her highest level of education and training was tertiary. She is permanently employed, and her support was her spouse and her mother. She expressed that she has feelings of depression and frustration at times. Pinky's greatest wish for her daughter with spinal Bifida was to be able

			to walk one day, to always be happy, and not feel left out.
7	George	Porencephalic Cyst & Physical Disability	George is a divorced 53-year-old father of seven children, and his eight-year-old has a porencephalic and a cyst. His highest level of education is secondary, and his training was secondary. He was unemployed and his support is from the child's mother and his family. He expressed feelings of stress at times. George's greatest wish for his son with a disability was to get an education and be something in life.
8	Simone	Autism Spectrum Disorder	Simone was a 30-year-old single mother of twin boys. One son has mild autism, and the other son has severe autism. She was permanently employed, and her support was her family. She expressed feelings of anxiety at times. Simone's greatest wish for her twin boys with autism was to lead a normal and healthy life.
9	June	Cerebral Palsy	June was a 28-year-old single mother of a 3-year-old daughter with cerebral palsy. Her highest level of education was secondary and a licensed practical nurse. She was unemployed and her support was from family members. She expressed that she has hypertension and has feelings of depression at times. June's greatest wish for her daughter with a disability was that she does everything a normal child her age should be doing.
10	Wendy	Autism Spectrum Disorder	Wendy was a 55-year-old grandmother of four children and caring for her 5-year-old granddaughter with an autism spectrum disorder. Her highest level of education and training was tertiary. She is permanently employed, and her support was the parents of her grandchild. She expressed that she has hypertension. Her greatest wish for her granddaughter with a disability was that she develops her different milestone and developmental stage.
11	Mother Hen	Developmental Delay & Intellectual Disability	Mother Hen was a 40-year-old mother of a 10-year-old son who was diagnosed with developmental delay and intellectual disability. Her highest level of education and training was secondary. She is unemployed, and her support was from families overseas. She expressed that she suffers from schizophrenia. Mother Hen's greatest wish for her child with a disability was for him to be able to read and write, especially writing his name.
12	Evelyn	Autism Spectrum Disorder & Speech Disability	Evelyn was a 49-year-old mother of three children, and she cares for her 9-year-old daughter with autism spectrum disorder and speech disability. Her highest level of education and training was secondary. She was unemployed, and her support was her spouse and older children. Evelyn's greatest wish for her granddaughter

			with a disability was that she may get over her disability.
13	Sandy	Autism Spectrum Disorder and Epilepsy	Sandy was a 57-year-old grandmother who cares for her 13-year-old grandson with autism spectrum disorder and epilepsy. Her highest level of education and training was secondary. She was unemployed and her support was family. Sandy's greatest wish for her grandson was for him to read and write.
14	Chrystal	Deaf and Speech Impairment	Chrystal was a 26-year-old sister who cares for her 13-year-old brother who is deaf and with speech impairment. Her highest level of education and training was secondary, culinary and cosmetology, and manicurist. She was self-employed, and her support is her mother. She expressed that she suffers from depression due to a slow chain of income. Chrystal's greatest wish for her brother with a disability was for him to live a fully normal life and for him to be happy.
15	Kiva	Physical Disability	Kiva was a 38-year-old single mother of two, and her 8-year-old son has a physical disability. Her highest level of education and training was secondary and culinary. She is permanently employed, and her support was her son's dad and her family. She expressed that she suffers from a rare disease called paroxysmal nocturnal hemoglobinuria (PNH). Kiva's greatest wish for her son with a disability was to be the best possible.
16	Brenda	Down Syndrome	Brenda was a 31-year-old married mother of two children, and her 11-year-old daughter has Down syndrome. Her highest level of education and training was secondary. She is self-employed and, her support was her brother. She expressed that she suffers from hypotension and PTSD. Brenda's greatest wish for her daughter was for her to reach her full potential and to receive assistance in every possible way.
17	Birdy	Down Syndrome	Birdy was a 59-year-old married mother of two children, and her 16-year-old son has down syndrome. Her highest level of education and training was secondary. She is employed part-time and supports her daughter. She expressed that she suffers from high blood pressure. Birdy's greatest wish for her son with Down syndrome was for him to be better after two major surgeries.
18	Shelly	Cerebral Palsy & Limited Mobility	Shelly was a 38-year-old married mother of two children, and her 5-year-old son has cerebral palsy and limited mobility. Her highest level of education and training was tertiary and her support was her spouse. She expressed that she suffers from depression. Shelly's greatest wish for her son with cerebral palsy and limited mobility was to not have a special need.

19	Keisha	Dandy-Walker Variant, Intellectual Disability, Large Left Arachnoid Cyst	Keisha was a 43-year-old single mother of 2 children, and her 13-year-old daughter has a Dandy-Walker variant, intellectual disability, and a large left arachnoid cyst. Her highest level of education and training was secondary and Heart Trust. She is Permanently employed and her support was her family. Keisha's greatest wish for her daughter with the dandy walker variant was that one day her daughter may be able to operate as much as possible as a normal child.
20	Molly	Physical Disability	Molly was a 30-year-old single mother of three children and her 12-year-old son has a physical disability. Her highest level of education and training was secondary. She was unemployed and her support was her spouse, family members, and friends. Molly's greatest wish for her son with a physical disability was for him to walk like a normal child and to get an education.
21	Pat	Autism Spectrum Disorder	Pat was a 38-year-old married mother of two children, and her 16-year-old son has autism spectrum disorder. Her highest level of education and training was secondary. She is unemployed but rears chickens occasionally and her support was her spouse and her aunt. Pat's greatest wish for her son was for him to be independent.

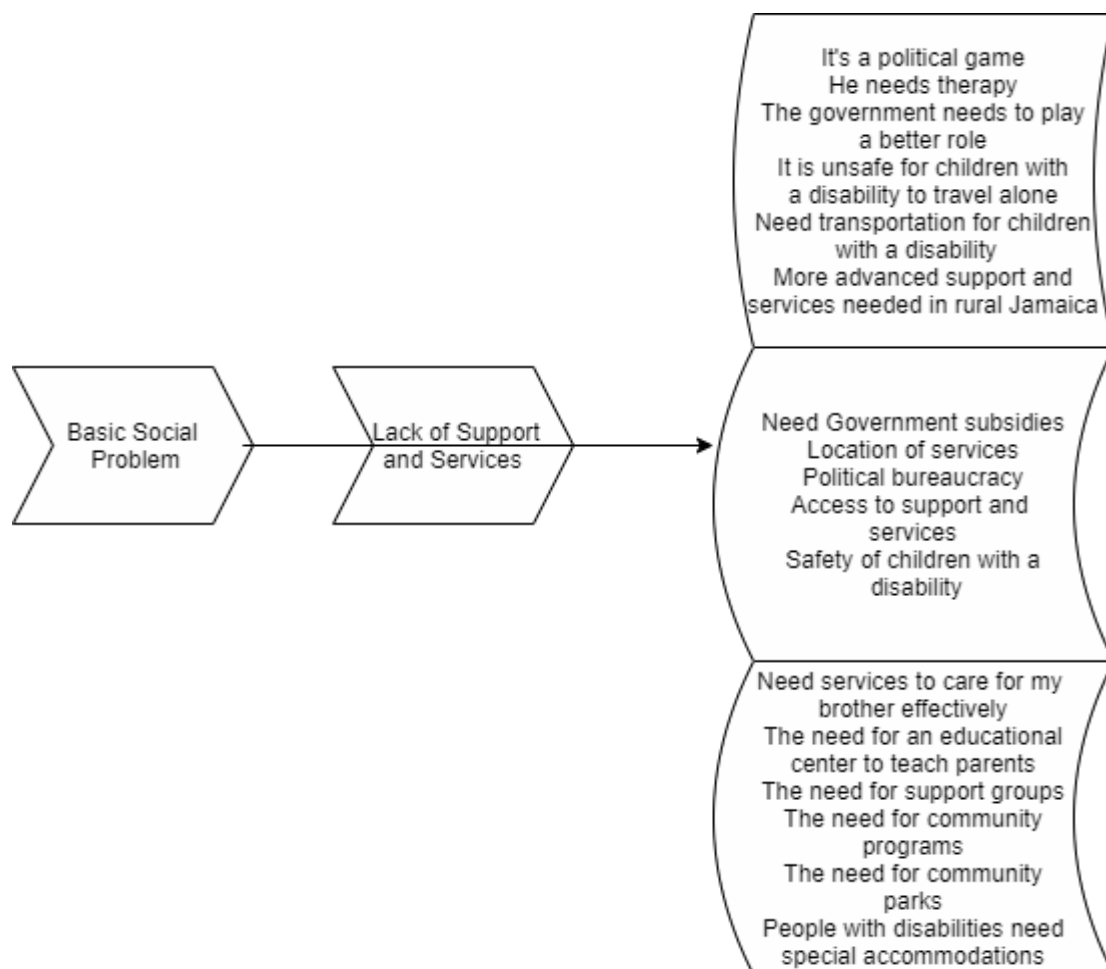
Basic Social Problem: Lack of Support and Services

The participants of this research study expressed the lack of support and services for children with disabilities in Jamaica. These benefits include providing information regarding the availability, quality, accessibility, and services, especially in the rural areas of Jamaica. There were many emerging themes during the interviews, but what appeared consistent across the findings and identified as the basic social problem was the lack of support and services. One parent reported spending all her money and having to borrow from others to pay for therapy for her daughter and not knowing when or how she will pay back her debt. Parents who were unemployed and lived in the rural areas were most affected, as services were not affordable.

Lack of support and services is a sense of disappointment for parents and guardians raising children with developmental disabilities in Jamaica. Without the support and services,

there is no hope or normalcy for the children. The bureaucracy of the government-subsidized support and services was frustrating. The government services were hard to access, and geological location made access impossible for some parents due to financial burdens. Lack of support and services was determined by the following theoretical constructs: burden, it's challenging, emotional and mental well-being, professional awareness, and social stigma. The lack of support and services is illustrated in the participants' quotes that follow (see Figure 2).

Figure 2: The Basic Social Problem: Lack of Support and Services



Basic Social Problem: Lack of Support, as Described by the Research Participants

Rosey was a 32-year-old single mother who lives in rural Jamaica and has a 4-year-old son with Dandy-Walker syndrome and hydrocephalus. Rosey's highest level of education of training was secondary. She was unemployed and her only support was from her mother. She expressed feelings of stress and depression. Rosey's greatest wish for her child with a disability was for him to improve. Rosey struggled with the political bureaucracy on how to access support and services.

In Jamaica that you would have access to it through your member of Parliament, which is the person who is responsible for your division. These are politically related so I tried my best not to engage or intertwine my personal life with politics because it can have a negative effect. How do Jamaicans say it? From "the man." All the funds come through your member of Parliament so there's always a political game played. It's like Jamaica Labour Party or Jamaica Labour Party person and if you're over on the PNP side and you want a little assistance, you're not going to get it because you are not one of them. Everything that you do, it's like everything, it has to be politically related. So nobody stays neutral. They just look at the color and who you are with and if you are not with them, well you do have any benefit or if you are with them, you have to know somebody who is in a high position or in a high seat or are close to the member of Parliament that can speak a word to you in his ears and he might consider your request, depending on how he thinks of the person. The only support that I really need. Honestly, I'm a fierce person and I'm also a very independent person. For me right now, what I really need is once it is that I find myself in a job, right when I can financially sustain myself, I just go off and branch off into a business that can generate more money. I know that that day's going to come that he's going to use up all of my salary, but just to have a second income coming in and just be the best mom you can be because there's no dad at all, and grandma is there to play a part.

Shay was a 29-year-old single mother who lives in urban Jamaica and has a daughter with a global developmental delay. Shay's highest level of education and training was tertiary. She was employed part-time and her support is her spouse. Shay's greatest wish for her daughter was for her to know that she loves her and will always be there for her. Although Shay has access to support and some services, she shares the sentiment of the lack of support and services of parents

raising children with developmental disabilities in Jamaica.

But the government really needs to play some part, especially around the people who have a special need to play more part. And look out for special people even more. A lot of them go to homes, they need to play more part, man. Give parents who have a special child a little more, help out, work, something. If they don't want to give them money, give them some work. Build some workplace for them, a workplace that understands parents who have children with disabilities. For example, if they need to take the child to the doctor. They need to do something more to help them. That's what they need to do because they have enough of them right now if they don't want to give money, give work. But the stuff some people have to go through because they need the help. They need to do a special line for the special people. Like I say, poor people and the people with the special people and the special child, just put them on that line. Some of them cannot leave their child alone, so they have to bring the child with them, even put the money in a bank account and if they don't have a bank, can't open a bank account, tell them to have a special line down there for special needs. Look out more for parents and children. Sometimes you stand in line and when you get to the front of the line, you are told that your name is not on the list.

Pinky was a 26-year-old single mother of two. She lives in urban Jamaica with her 8-year-old daughter with Spina Bifida. Pinky's highest level of education and training was tertiary. She is regularly employed, and her support was her spouse and her mother. She expressed that she has feelings of depression and frustration at times. Pinky's greatest wishes for her daughter with Spina Bifida were to be able to walk one day, to always be happy, and not feel left out. She lacks support and services for her daughter with Spinal Bifida.

Well, we could have a community program where persons who need help could come and talk and everybody could unite as one and probably help each other or seek help. Because she wears Pampers and I have to use wipes and I have to always have stuff like food, everything because I have to help her, she can't help herself. I have to always have everything. So it's like taking care of a baby, like when she was born. The only thing she can talk about. So it's not like I have to be wondering what if she crying for. She talks to me and she understands. So, if there was a community-building or center around here, that could help. What I think they could put in place, would just help to have a community center where we could just come there and if they can help, or seek help, that would help me. For example, you can have some persons who donate help or donate even money, and it could go toward her.

George is a divorced 53-year-old father of seven children living in rural Jamaica. His 8-year-old has a porencephalic cyst and a physical disability. George's highest level of education and training was secondary. He was unemployed, and his support is from the child's mother and his family. He expressed feelings of stress at times. George's greatest wish for his son with a disability was to get an education and become something in life.

Basically, I need support; it is financial, as I said, I'm not working now, I don't have a job right now, and I'm taking care of him because his mother is not here, so I have to take care of him 24/7. But if I could get some financial aid, I would be grateful, that's my main problem. Okay, as I said, if there was a program, or should a program be put in place, like financial, to help parents because I can't go out and work because of my son, and because of his disability. I think about it at times, and I. Yeah, if there was a program such as you could leave a child at a place or at a daycare center, let them off X time and pick him up X time, I could go and do some work, but there is no such thing in my community that fit our needs. If he could get that kind of assistance, then I would be grateful. Because I would do things on my own, instead of depending on other people. Those are some of the things I would love to see put in place.

Simone was a 30-year-old single mother of twin boys who live in urban Jamaica. One son has mild autism and the other son has severe autism. She was regularly employed and her support was her family. She expressed feelings of anxiety at times. Simone's greatest wish for her twin boys with autism was to lead a normal and healthy life. As a single mother of twin boys with Autism Spectrum Disorder, Simone struggles with the location of services.

Aside from the Jamaica Autism Support Group, I'm not aware of any major groups as such. The school that they attend, they are very supportive. I think they're brilliantly trained teachers who get it, and they're very supportive of parents. And the thing I like about them is that you can be honest, and you can be yourself. When we go to a parent-teacher meeting, we can be ourselves and we can be honest. Because, as I said earlier, it's almost like you have to put on this facade that "Oh, everything is okay, and I am the best parent, and this is the best child, and life goes on." But that is a big support system for me, school. Yeah. But anything else outside of that, I'm not aware. I will say there maybe, but I'm not aware of it. Okay. Well, some of these services and mostly the fees are exorbitant. For example, the one that is non-verbal, though I say non-verbal, he speaks when he wants to. But let's call him non-verbal. Speech therapy, for example, I don't know how you calculate this here versus in the States. But half an hour of therapy

is probably J\$8,000. So, maybe that's roughly \$100 US dollars or something. I don't know. Thereabout. Right? And a half an hour, they want to see you at least times for the week. So you know an hour is double that. So, probably \$110 for an hour. You do that three times a week. These modalities are not covered under your health insurance. So, we have to pay that out of pocket. Most of these services are offered in a centralized area, which is Kingston. But, if you work outside of Kingston and live outside of Kingston, you have to think about making time from work to do the session with the child they have in school. But I would want to see possible whatever ministry or therapy. Have these therapies go into the schools for regular visits for students such as my son who is non-verbal, to get him behavioral therapy and speech therapy. Doesn't have to be free, but if I don't have to travel by bus or taxi, I take time from work, which will become a problem eventually, then that's something I would like to see. Make it more accessible where they actually go to the children. Because to be honest, in this school that they attend, a lot of the parents are unemployed. They're not working, and the children need support services, but we can't afford it. Even if you have a stable job, it is not cheap. It's not cheap. Behavioral therapy, that's J\$10,000 for an hour. For the average Jamaican, as much as you want to help your children, it's not always feasible to do that. So, that's something I would want to see. If it is available, you will find those in the prep schools. That's the department of special needs, so to speak, in the schools. But, for these other schools that are not. What should you call it now? Prep school, that are not \$100,000 terms for, you find that the support services are not there. So, them sending these therapists to the schools at whatever cost, even if it can be subsidized, would greatly help, because at the end of the day, it's going to benefit the children. So, that's something I would like to see put in place.

June was a 28-year-old single mother of a 3-year-old daughter with cerebral palsy who lives in urban Jamaica. June's highest level of education was secondary. She is licensed as a practical nurse. She was unemployed and her support was from family members and her daughter's father who lives abroad. She expressed that she has hypertension and has feelings of depression at times. June's greatest wish for her daughter with a disability was that she does everything a normal child her age should be doing. June expressed the need for government subsidies, especially for single parents.

I don't get any support. I've been trying to get her on the PATH Program, and they turn her down more than one time. Well, I think the government put something in place where they even provide food for them. That would take a lot of pressure off the parent because sometimes we as parents have disability kids and the father is not there. Basically, sometimes the parent is alone with that child. And with that child, you cannot really work, you have to sit down and take care of

them because basically, remember I told you that my child wasn't walking until she was three. And she just starts walking a month ago. I wouldn't even say three because she's almost four now. It's very challenging.

Evelyn was a 49-year-old mother of three children who lives in rural Jamaica and cares for her 9-year-old daughter who has autism spectrum disorder and a speech disability. Evelyn's highest level of education and training was secondary. She was unemployed, and her support was her spouse and older children. Evelyn's greatest wish for her daughter was that she may get over her disability. Evelyn expressed the need for more advanced support and services in rural Jamaica.

No, there is no support and very little services. They have a special ed school, but they need a lot more there. They try their best and things like that, but I guess we need much, much more so that they can be improved. So, there's not, apart from the school that she goes to, there's a school in Kingston but that's more advanced. And they have one and one in Montego Bay that they say is more advanced, but I live in bay. They have a school there where. but they try but it's not like that. they don't do speech therapy there. They mostly do like, in her case, what I've known is that they do stimulation, with her brain and using her hands. And she gets her basics also, like [a toddler learning aid]. Well, a center where you can leave them after school. That would be very, very, very, very good. What else would I want? Just a center for like after school and someone to spend. like a shadow. Yes, I would love a shadow, so that would be good. And. what else? Basically, for more speech therapy like after school, to spend more time. A teacher to give her more help with her speech.

Sandy was a 57-year-old grandmother who cares for her 13-year-old grandson with autism spectrum disorder and epilepsy. Her highest level of education and training was secondary. She was unemployed and her support was from her family. Sandy's greatest wish for her grandson was for him to read and write. Sandy expressed the need for special transportation for children with disabilities. She was concerned that it is unsafe for children with a disability to travel alone. During the interview, she shared an incident that took place in Kingston.

I don't know of any support. Try doing some chicken rearing and sell snacks and water to support my family. They should have special transportation for children with disabilities. It's not safe for them to travel alone. They should also have

programs special programs for parents of children with special disabilities so that they can survive financially.

Crystal was a 26-year-old sister who cares for her 13-year-old brother who is deaf and has a speech impairment. She lives alone with her brother and is the full-time caregiver as her mother lives “overseas.” Crystal’s highest level of education and training was secondary with training in culinary arts, cosmetology, and as a manicurist. She was self-employed, and her support is her mother. She expressed that she suffers from depression due to a slow chain of income. Crystal’s greatest wish for her brother with a disability was for him to live a fully normal life and for him to be happy. Although Crystal is not lacking in financial support because of the financial support from her mother and her brother’s father, she still needs services that will support her so that she can care for her brother effectively. She describes the need for her brother to communicate better and the limited resources that are available to help caregivers with communication deficits.

It's never been that hard, I can say because if he needs anything, my mom will provide it. Or his dad would provide it. So I didn't want to say we really needed any major financial help or anything like that from the government. They did a program a few years ago, where they had a bunch of parents did a weekend at a resort where they were teaching us some sign languages and they taught us about the benefits from the government and other stuff that we can do to help with our child with disabilities. It wasn't something that was provided in every parish, because it was at a hotel in Trelawny, and there were parents from Kingston, Manchester. It was all over, but they had to travel so far. So if they had something in each parish, a major area in each parish where the parents can go there to learn sign language so that they can be better able to communicate with their child. That would be a very good idea, which they said that they were trying, but I haven't heard anything much about it after that, two years ago. I heard that they'd done it before, and I think they did it again, but it was another parish. They do it at different parishes.

Keva was a 38-year-old single mother of two. Her 8-year-old son has a physical disability. Her highest level of education and training was secondary and culinary arts. She is

regularly employed, and her support is from her son's dad and her family. She expressed that she suffers from a rare disease called paroxysmal nocturnal hemoglobinuria. Keva's greatest wish for her son with a disability was to be the best possible. Keva stressed the importance of having a center to teach parents who are raising children with developmental disabilities. She stated that a center would be beneficial to those parents who live in rural areas.

I suppose I didn't know anything about getting any help or anything, or any resources to help him. And I think maybe when I about the persons for disability fund, the fund for persons with disability, something like that, it would be applicable for him and then when it's time for him to go to school, I think the social worker see him and said he should be a part of the fund because of his condition. But as I said, this school, I don't think Jamaica reached there yet, and I don't know when, how long, but there is more needed to do for people with disabilities. Finance. That's one because having a child may be, who cannot walk, not at all and maybe that parent suddenly needs a wheelchair. In Jamaica, everything you have to buy. There's nothing really free. Finance is one. Emotional support is one. I don't know, there are so many things that are needed there. Looking at it now, there's so much work to be done. we're not going to get there now, but finance is important, emotional support is important. I think maybe that's one of the most important things is having somebody to talk to, maybe cry on their shoulders. Life is not lost; he is not the only one. That would maybe encourage the parents and give them hope. A school, a child's center, or something for persons with disabilities. It would be very beneficial to have a school where you train the parents, the family members who are dealing with this disability. Hands-on. So you don't have to be alone or afraid, you don't have to feel that no one cares, that's something that parents will just support from. Teach parents how to surf the internet, especially in remote areas, because everybody else is using the internet. If these communities have specific places where you come to learn about what is a disability? You can help someone you can stop when somebody is scared, stops you, help you whether it be emotional, finance, whatever, that would be good because I don't believe that people understand how challenging it is to care for a child with a disability, especially in Jamaica. Trust me, we need it.

Brenda was a 31-year-old married mother of two children, and her 11-year-old daughter has Down syndrome. Brenda's highest level of education and training was secondary. She is self-employed and her support was her husband and brother. She expressed that she suffers from hypotension and post-traumatic stress disorder. Brenda's greatest wish for her daughter was for her to reach her full potential and to receive assistance in every possible way. Brenda suggested

the need for more support groups, as these groups help parents to deal with the challenges they are facing with caring for their child with a disability.

There is no support really. There are challenges sometimes, especially because I'm self-employed, so I have to actually go look for persons to sell my products, and I do another business. I have to do that to support her financially because I do not really, how should I say, with the support that I get from family is more physical. Like they will assist in caring for her. The financial part is on me and her dad and my husband. Well, they should have more support groups. I'm part of one, it's not common in the senses that many persons don't know about it. I only became a part of this support group, because I used to take her to Kingston for a checkup. She did heart surgery there and a doctor introduced me to the program. That's how I became a part of it. A lot of mothers are not aware of it. Yes, I introduced a couple of mothers to it to help support each other because they come with a lot of challenges, and I know some parents are not equipped mentally to deal with it.

Birdy was a 59-year-old married mother of two children. Her 16-year-old son has Down syndrome. Birdy's highest level of education and training was secondary. She is employed part-time with some support from her daughter. She expressed that she suffers from high blood pressure. Birdy's greatest wish for her son with Down syndrome was for him to be better after two major surgeries.

I've tried and have not gotten anything as of yet. From when we did the surgery, I ask for help and I've not received anything as of yet. I sent to the ministry, I've sent to Kingston, I've sent to all the available associations to help me. I haven't gotten anything. I don't know if it's because of the COVID but I have not gotten any help. They should put things in place where parents who have children with disabilities can get work nearby; we can get more assistance from the government. And as a single parent, I pay rent and if the government could assist in housing, that would help a great deal. I wouldn't want him to leave me because I love my son. I wouldn't want him to be taken away from me, but I just need something to help me, just financial help right now.

Shelly was a 38-year-old married mother of two children, and her 5-year-old son has cerebral palsy and limited mobility. Shelly's highest level of education and training was tertiary and, her support was her spouse. She expressed that she suffers from depression. Shelly's greatest wish for her son with cerebral palsy and limited mobility was to not have a special need.

Shelly is fortunate to have services at the school that her son attended, but she stated that as her son gets older, there are services that she would like to see available for him.

Well, the school that he attends, it's a government-based school, and that same school offers physiotherapy. So, I no longer have to leave work, take him to a therapist, take him back to daycare, get back to work. So, that has been a plus for me, that where his school is, the therapist's school's there and does what needs to be done. Well, the school is fine because the school also offers aftercare, so even though school ends and I'm still at work, I'm able to leave him there until work ends, then I can get him and it's good for now. As he gets older, there are other resources that I might be able to tap into in terms of, there is an option, I understand, to have. I'll tell you the name of what it's called in a little bit. It's called a shadow, that is someone that you can have with him all day while he's at school. So, he should be able to be integrated into regular schooling, but a regular teacher would not be able to have her eyes on him and everybody else at the same time and he could get injured. So, if he had a shadow with him if he needs to go to the restroom, he gets it, if he needs to move around, there's always somebody there with him. If we see that he's able to accelerate into regular schooling but still has some limitations, then that should be a resource that I can apply for in terms of how easy it is to get a shadow through the government. I'm not sure, but it is something that exists.

Keisha was a 43-year-old single mother of two children, and her 13-year-old daughter has a Dandy-Walker variant, intellectual disability, and a large left arachnoid cyst. Her highest level of education and training was secondary with vocational training from the Human Employment and Resource Training Trust/National Training Agency, known to most Jamaicans as "Heart." She is permanently employed and her support was from her family. Keisha's greatest wish for her daughter with the Dandy-Walker variant was that one day her daughter may be able to function as much as possible as a normal child. Keisha expressed her frustration about the time frame in which it takes to access services, the distance to get to services, and the financial cost to parents and guardians trying to access services. She mentioned the need for programs and parks in the community.

There is not enough support or services for parents who have children with a disability, not really. She's with the Jamaica Council for Persons with Disabilities. So that's really where I would get any form of assistance, I get assistance from

them. Because even with the housing now, I am going through them, along with others like National Housing Trust. Well, I have tried; I have been trying for more than a year now to get her in a program that we have that's called a PATH program. Monetary funds, like paying school, they would get lunches and stuff like that. But to date, I still have not heard anything from it, and each time I ask, they said that they're a week, and another week and they're supposed to be some. I am not sure if we can request these care packages from UNICEF and those places. Yes, yes. That would be good, that would be very good. Daycare would be another thing, because as I say, if there was such a daycare that was for them specifically for children with special needs, then I think that would take some pressure off some of us. Because I would think it would at least help parents like myself, because then we will be able to work, so we drop them off. It's the therapy. It's like report cards, you need someone to help with their mobility, like move on their own, occupational therapy. There is a big problem, the organizations are not close by. You will find one all the way in Kingston, you find another one all the way in Montego Bay. So we don't really get these accessibilities. To get these, you have to have huge money. And then to get the others, some of them are located in places that you can't get to. So that would be good if we could have something like a facility in the community. Maybe therapists can visit once a week. I guess I would say a park also, a recreation park that we can take them to. That would be good. We don't have things like a park for children with disabilities. There's one park in Ocho Rios, It's not much of anything in there, just for normal children. I took my daughter there once and I don't take her back, because there's really not much for her to do.

Pat was a 38-year-old married mother of two children. Her 16-year-old son has autism spectrum disorder. Her highest level of education and training was secondary. She is unemployed but rears chickens occasionally and her support was her spouse and her aunt. Pat's greatest wish for her son was for him to be independent. Pat expressed the need for better services to assist with medication and transportation for children with disabilities.

In my community, there are no resources or support whatsoever. Like sometimes he's on medication, and it is really rough sometimes. The government should have a special medication program for them. Some of them are on medication to save their lives and parents should not have to worry that they can't get the medication or afford the medication. Sometimes I don't even get it at the health center. They should also provide transportation to school because he can't travel on his own. So I have to bring him to school and take him back home and go back for him. Do you think they could set up a trust fund for children with disabilities? Like to help with medication and transportation, stuff like that. I think they could have a program where mothers could join like a group, where you have a club. You get some speakers and some lecturers come in and talk to you and give you counseling so we can better understand our children's disability.

Core Concept: The Challenges They Face

The challenges they face were identified as the core concept that was connected to the basic social problem of lack of support and services with parents raising children with IDD in Jamaica. The core concept of *the challenges they face* is defined as the recognition of some of the challenges that parents and guardians are faced with in raising their child with an IDD. Parents raising children with an IDD are faced with everyday challenges and most often are left to figure out how to manage on their own. Many parents suffer from stress and frustration due to the inability to cope with the daily needs of their child with a disability.

Researchers have suggested that caregiving, activities leading to subjective burden involves many aspects of caregiving, including the caregiver's physical health and a restriction in the caregiver's social activities. Therefore, the care recipient's behavior and physical needs resulted in a gradual increase in stress and burden for the caregivers (Grael & Adabbo, 2011; Smith & Shinebourne, 2012). Parents raising children with IDD have self-identified the challenges they face.

Data collection and constant comparative analysis occurred concurrently, consistent with grounded theory methodology. The core concept occurred frequently in the data with other categories related and attached to the core concept. The core concept of *the challenges they face* is the central idea that emerged from the data and is able to explain variation in the information.

Five Theoretical Constructs Attached to the Core Concept

Five supportive theoretical constructs surround the central process of the core concept as *the challenges they face*. The surrounding concepts included the concerns they face as parents/guardians and the burden that their child with a disability will and can be to others. It's

challenging for the parents raising their child with a developmental disability; the emotional and mental well-being of the parents and guardians who are raising the children with a developmental disability; the professional awareness; and social stigma that parents experienced from doctors and nurses and from society for their child with a disability.

Theoretical Constructs: Burden

During the interview, parents shared the various challenges and experiences in raising their child with a developmental disability. Most of the mothers were single and unemployed without the active presence of the father in the child's life (see Figure 3). One parent spoke in depth of the father's disappearance when she told him of her pregnancy. Rosey spoke about the financial burden she faced as a single mother and her frustration with the father of her child who doesn't help out financially. She described her situation as being "tight," especially now that there is the Covid-19 pandemic.

The family suffered greatly, especially me. Well, for me, personally is dreadful. Dreadful in terms of don't have the financial, the finances to come back some of the requests that the doctors have been given. That is number one. The family support was not good, the person that I have is my mother, so my mother supports me. I actually suffered mentally and financially wise because there are certain things that need to be done and it couldn't have gotten done because of financial need. Furthermore, the father was not doing what he was supposed to do on the other hand to help to pull through with the request of the doctors.... because there's nobody to help but in my case personally, I find myself in terms of frustrated, because if it is not me, it's mom. And it just rotates between the both of us. Finances, and his numerous admissions, we're always there, we have to be talking to nurses, doctors, and everyone. Understand? So it is stressful and burdensome when you don't have the finances, but when you're in a family that has it, it cushions certain pressure from you and gives you some form of mental. You feel a bit lighter because you have family members that can chip in and are dedicated to you and the child, especially to say, "All right, let's all do this together as a team," versus somebody that doesn't have a team. They just have to go solo. So that's it because the situation that we're in right now is that as soon as my son kind of relaxes and he's stable, and once it is that I realize that my son is stable, I'm job hunting. COVID is actually coming in now. It's really, really tight now but if you've never had a job before, you're not going to have a job now, have a job so easy right now.

Kay was a 27-year-old mother of two children. Her 7-year-old son has Down syndrome. Her highest level of education and training was secondary. She was unemployed and her only support was her aunt. Kay expressed that she has hypertension. Kay's greatest wish for her son with a disability was for him to be able to speak. Kay struggles with not having anyone to attend to her son if she has to go places.

Yes.... I see it as a burden because sometimes when I go somewhere and I don't have anybody to keep me. I don't really cry, but I just worry and wonder if he is going to walk and talk.

Joy is a 61-year-old single mother of four children. Her 16-year-old son has Down syndrome. Her highest level of education and training was secondary. She was unemployed and her support was her child's father. Her greatest wish for her son with Down syndrome was to see him become something good in life. Joy is concerned that her son is getting older and there will be new challenges. She spoke about the financial challenges in caring for her son and the difficulty in caring for him and how it impedes her ability to work outside the home.

And it's getting hard. And now he is getting bigger. If I have to go out and I don't have anyone to keep him, I take him with me. I need financial help... If I can get some financial help, I would be grateful. He needs other things and I'm not able to afford it right now, but it's kind of hard. He needs educational toys. Toys to help develop his education. He also needs therapy because we don't understand him sometimes when he speaks.

.... And it is difficult, for sometimes getting ready to go somewhere outside. It takes a while, not as a normal child would take. If you are telling him anything, it takes a long to absorb it. I can't work as I would want to. I have to stay home with him. There was a time when I used to take him to school and wait until school is dismissed, but now, I have a taxi operator doing it. It's very hard. It's very pressuring. His father used to help, but now he has to go to work. Sometimes, if I have to go anywhere, I leave him with a neighbor if.... I trust my neighbor who I leave him with.

Ms. Brown was a 45-year-old married mother of four children. Her 18-year-old daughter has a speech impairment and heart disease. Her highest level of education and training was

secondary. She was unemployed and her support was from her spouse and her older children. She expressed that she has diabetes. Miss Brown's greatest wish for her daughter with a disability was to be able to speak properly. Miss Brown stated that because of the coronavirus pandemic, caring for her daughter has been rough.

It's rough now. Because when my daughter was working, she helped with her, and now it's like. . But because of the Coronavirus, they are not working at the moment. But we are trying to cope.

As a single mother, Pinky spoke candidly about the burden of raising her daughter alone. She stated that she loves her daughter, but it's hard when you are young, single, and only 26 years old with little or no financial support from her daughter's father.

Oh Lord, this is just hard. I wouldn't say it is easy. Really, it is hard and the fact that I'm young, sometimes I'll ask God. Well, I used to ask God, "Why me?" Yes, it is a burden because you have sometimes where, for example, I will just change her, and she said, "Mommy, I doo-doo again." And then I was like, "Oh lord, I just changed her." And then I have to change her. She's getting older, so it can be very difficult to keep on lifting her, changing her. When you finally sit down and relax because it makes you tired. And then when you finally get a chance to relax. It's worse when you're a working person especially with the school, it's like you just always have to be working whether it's school, homework, or at home. It really affects me and my mommy because her father is not really around. For the entire year, he would call sometimes. He's not in a stable job. This moment he's working, next moment he's not. I don't really get that support and help from him. I really get it from my mother. So my mother plays the role for him. And then she has to lift her and she's going to be eight this month, so it's going to be a little bit straining on her and on me as well. Like when we're supposed to give her a shower and stuff like that.

George was a divorced single dad who received support from his immediate family. He expressed that he needs financial support as he is unemployed, and he is concerned about this son's future as well.

Basically, I need support financially, as I said, I'm not working now, I don't have a job right now, and I'm taking care of him because his mother is not here, so I have to take care of him 24/7. But if I could get some financial aid, I would be grateful, that's my main problem. Sometimes when I realize that it's kind of difficult for him to manage sometimes. I think what's going to happen when he becomes older and honestly, sometimes, it chews me up emotionally.

As a young mother, June spoke about the burden of adjusting her lifestyle. Like many of the mothers in the study, June is unemployed, and her child's father resides abroad.

It was a burden because as a young mother, you basically cannot do what you're used to and you cannot work, so you cannot fend for yourself, so you have to depend on people. Having her, she cannot walk because she just a month ago. Everywhere I'm going, I have to take her with me. Sometimes, if I get a job, I can't find anyone to leave her with because at one point she wasn't eating from anybody and she just did bottle, she doesn't eat food and it was just a burden. I don't think I get the support from her dad's side of the family, but I got full support on my side. On her side, it was just her father and then at two years old, her father migrated and basically, just her and me. Even though he's not in Jamaica, I still don't get the support I think I'm supposed to get from his side of the family that is living here...so that makes it hard as well. Her father does help where financial support is concerned.

Mother Hen was a 40-year-old mother of a 10-year-old son who was diagnosed with developmental delay and intellectual disability. Her highest level of education and training was secondary. She is unemployed, and her support was from families living "overseas." She expressed that she suffers from schizophrenia. Mother Hen's greatest wish for her child with a disability was for him to be able to read and write, especially writing his name. Mother Hen spoke about the financial burden of raising her child with a developmental disability. She is also faced with the burden of guilt and caring for her mother who has some health issues of her own.

Financially, it's hard. I would be grateful for some financial help. I am not working and his father is not working ...so financially, it's hard. I am sick myself...I have some mental challenges myself. I think he is delayed because of me... Before I found out that I was pregnant, I was on medication...so I don't know if that contributed to his disability. He gets PATH but that is not enough...It's every three months. The church helps me with clothes and school supplies sometimes...but that's it. There is nowhere else to get money or help from. I can't afford toys and clothes for him.... like an educational toy.

Keva spoke not only of the financial burden but also about the burden of raising a child with a developmental disability. She described this as the many different doctor visits, the many hospitalizations, the emotional burden, and the future of her son.

To be honest, it was hard. Finance. That's one because the thing is it's not only the disability that's the challenge. It's other medical conditions, the different specialists.... the hospitalization. I thank God for his dad because he was always there. Finance is important, emotional support is important. I think maybe that's one of the most important things, having somebody to talk to, maybe somebody to cry on. There are times when I sit and ponder.... I see him and I wonder what's going to happen to him? How is he going to manage? And he is going to get there.... what does the future hold for him?

Birdie was a single mother who is raising her younger daughter as well as her son with a disability. Her son recently had surgery and was still hospitalized. Although she is able to work at times, she spoke about her financial burden and the burden of visiting her son at the hospital.

Birdie also spoke about the fear of her son being taken away from her.

It's quite a lot now because I am a single parent and it's just me and my daughter; we all live together. It's only the three of us ...sometimes, I have to prepare for both of them. I have to deal with his disability to help him around, take him to school and he doesn't have a special bus to take him to school, and sometimes that affects me a lot. He fell, and he did his vertebrate bone in his leg, and that caused him to damage his spinal cord ... But he had the surgery and he is still in therapy. And it's expensive and it's hard because I have to take public transportation. I take a bus from where I live to go into Kingston and then another vehicle to where he is atand sometimes my sister has to go with me because I have to take stuff for him. I have to take food stuff for him every weekend and he wears Pampers and has to take all those things for him on public transportation. I wouldn't want him to leave me because I love my son. I wouldn't want him to be taken away from me, but I just need something to help me, just financial help right now.

Shelley was concerned with the burden her son with a disability would cause to others as he was getting older and needed to be lifted and carried.

He's not a burden to me, but I sometimes worry that he might be a burden to others because he's getting older. So, he has to be Shelly sometimes and held, and he's not light. Because I mean, with the disability, it means that he is bearing down with even more weight because he's trying to do something as well, but then he pushes excess weight on you when he's trying to do something. So, he's bearing down on you a lot. So, I mean, for us, he's not a burden because he's ours, but when you think about leaving him somewhere, you kind of hesitate because you're saying, can anybody else understand and be able to be okay with this?

Keisha spoke about the difficulty of not knowing who to trust with her daughter who has a disability. She expressed not having anyone to care for her if she has to go places, and so she has to take her wherever she goes. She was concerned with her growing up and not being able to verbalize if she is being abused by anyone.

It's too difficult, because even with that time when I went on the weekend, no, you can't get somebody who you trust; the fact that you have to constantly watch her, that is hard for somebody to keep her. It's not just like you can take your mind off things and sleep it all off. But then it all falls down again because I have to keep her, I don't get to do anything. It's just from work to home and to church. Before COVID here, I did go to church for the last 20 years. But I try to really go to online services. It affects me and even there at work, every year the company pays for us to go on vacation for an entire weekend. And every year, I have to take her. Every year I take her. So it's even when they say, "Here, you take a break. Please note that you can just go and enjoy yourself." Every year I take her with me. Every year, I have to take her with me. And so, I don't get to go out to socialize. Anywhere I am, I have to have her with me because she's 13 now; she will be 14 this month, and I can't trust anyone with her. Because she cannot explain herself, or if she's walking now and she's walked in the wall, or she hits her anywhere and she smacks the wall or hits my floor, she can't come to mommy and tell me what happened... So a bump in the wall, or a drop, she doesn't notice anything at all. So I can't let go of my guard, I have to just keep her. When I go to work, I have to pay someone to stay home with her and that is very expensive but I have no choice. I have to do what I need to do.

Molly was a 30-year-old single mother of three children, and her 12-year-old son has a physical disability. Her highest level of education and training was secondary. She was unemployed and her support was her spouse, family members, and friends. Molly's greatest wish for her son with a physical disability was for him to walk like a normal child and to get an education. Molly spoke of her financial burden, especially whenever she has to travel back and forth to Kingston.

Financially, it's a burden. Taking care of his medical bills and going back and forth for his doctor's visits in Kingston puts a strain on us. It has been hard, especially whenever he is admitted to the hospital. Going back and forth to medical appointments is no joke when you are unemployed. I can tell you that there were times when we had no clue how we would get to Kingston to see him when he had his surgery.

In summary, parents raising their children with intellectual and developmental disabilities expressed their various burdens in raising their children with IDD. The most common burden was a financial burden. Some parents were concerned with the child being a burden to others, while some felt the burden of guilt for their child's disability.

Theoretical Construct: It's Challenging

Some study participants shared the burden of raising their child with a developmental disability, but some parents/guardians expressed that raising their child with a developmental disability was challenging but not a burden (see Figure 4).

Shay shared that her daughter was the reason for having a job.

She's a blessing to me. I know there are times when it's challenging, but she is not a burden. I let everyone know that she is a special child. Yeah... I want to make that clear in the opening because I let everyone and everybody know she's our special child. Everywhere we go, I just have to bring her. I know that she is a blessing... The school where she goes, that is where I'm working at. That is why I say she is a blessing. She never misses me, or I'm gone or whatever, I'm always there. People will say, "Mom, you are always there." A lady told me she never wanted a special child. She turned to me and said, "But when I see the way you care for her, I would take a special child." She also said I need to have a page for her because of the way I fix her up.

Simone expressed that it is difficult raising twin boys with a developmental disability.

She stated that it is frustrating and it is challenging but it's not a burden.

I'd like to say that I'm a very open person, and I like to speak honestly about these things. Because I feel like having children with autism or any disability, I feel like if you express how you really feel, people have a tendency to look at it like you're a bad parent. If that makes any sense to you. For me, it's hard. It's not a burden, but it's not easy. You think about a regular nine-year-old who is normal. But when they're nine and they have these challenges, and if it's your child throwing things down the toilet that belong to you and flushing it. Do you know? It's a lot of things. And it's frustrating, and it's difficult being a parent. It is not a burden; I don't perceive it that way. But it is challenging. Sometimes, honestly, I don't want to do it, and that's the truth. You don't want to have to deal with it, because it is so much sometimes. It's like you genuinely want to give up, but you don't. But it's just

that feeling, because you're human, and it's not an easy job, and it's multiplied by two. So, I wouldn't say they're a burden, but I would say that if I am honest, it's a challenge, and sometimes I just don't want to be a parent. You know the situation, especially when the father is not playing an active role, and you have to be the one who deals with it. Do you know? The behaviors in school, getting them into the right school program. Everything rests on one person. That is probably where the burden is, but not the children themselves.

Wendy was a 55-year-old grandmother of four children and caring for her 5-year-old granddaughter with an autism spectrum disorder. Her highest level of education and training was tertiary. She is permanently employed, and her support was the parents of her grandchild. She expressed that she has hypertension. Her greatest wish for her granddaughter with a disability was that she develops her different milestone and developmental stage. Wendy realized that she is learning from her granddaughter who has a developmental disability, and although it is challenging, she does not perceive raising her granddaughter as a burden.

No, I don't. Honestly, because it's not a burden because I actually see things and I'm learning some are things that I never was aware of with children who are autistic. But it is challenging. It's not a burden to me, and there are things that I see she's doing that make me feel good. Honestly, it's not a burden too, because I actually see things and I'm learning some are things that I never was aware of.

Evelyn spoke about how she has learned to be patient from caring for her daughter with a developmental disability. She expressed that she gets frustrated at times, but it is not a burden but can be challenging at times.

I wouldn't say it is a burden raising her. I just- sometimes it's kind of having fun with her, but sometimes you're more on the frustrating side. So I wouldn't say it's a burden because there's sometimes, I like her optimism and sometimes she makes me laugh and we laugh. So . right. But at times, with her challenges, we expect her to do, which we know she cannot do, certain things or to understand certain things that are said. So sometimes that can get you frustrated and it can be challenging at times. And it's a challenge with helping her because you have to do, obviously, kind of everything for her. She's nine years old. She will do self feeds, but she causes a mess. So she will feed herself, but she causes a mess. She will put on her clothes, but she takes long, and to do any other thing, you have to be at her, and it's really rough. It's a challenge. So sometimes the noise, sometimes she makes a lot of noise. And my son sometimes has to study and it affects him.

Although Sandy is unable to work, she expressed that it is not a burden raising her son with a developmental disability, but it is challenging.

I don't see it as a burden, but it is challenging. I can't work because I don't want to leave him with anyone. I don't want anyone to ill-treat him and people don't understand him... so I take him everywhere with me. I used to carry him to school and pick him up, but due to the coronavirus, his school closes down.

Crystal spoke about the challenges of communication with her brother with sign language, but she stated that he is patient and independent, which usually gets them on the same page.

No, he is not a burden at all, because he is very independent.... He is very responsible. The only difficulty is because he goes to a sign language school. He does speech therapy as well, but because most of his understanding is through sign language and I don't speak that language fluently, so sometimes, there might be a bit of a misunderstanding... like when I'm trying to tell him to do something or asking for something. But because he's such a patient child and he's always willing to teach, we end up getting on the same page after a while. I was going to say the only difficulty we have is communication, sometimes that can be challenging.

Brenda discussed that raising her child with a disability was not a burden. Although there were some financial challenges, this was her first child and her family was very supportive.

No. It wasn't a burden, because she was the only child here in the home so it was not. And I had support from my mom and her dad when he was around, yes. So I had support and my mom [inaudible] and my brother too. Everybody helped over there. It costs more financially too. Because they take longer too, to stop using diapers and you have to spend more on stuff like those.... And she was always having a cold, so that would cost money to go to the doctor. It was a bit more costly. It was a bit challenging when you think about the cost.

In summary, the concept of *it is challenging* was a common theme throughout the data. Some of the parents/guardians expressed that it was not a burden raising their child/children with an IDD, but it was challenging. Some parents/guardians shared their frustration, some their content, and one parent mentioned that "she was a blessing." Regardless of the challenges they face, some parents did not perceive raising their child/children with developmental disabilities as

a burden.

Theoretical Construct: Emotional and Mental Well-Being

During the interviews, parents and guardians came to terms with their emotional and mental well-being. Many of the parents expressed how they felt when they were told that child/children had a developmental disability and how it has affected them emotionally and mentally. They discussed their coping mechanisms and how raising a child with a developmental disability has affected their family and their social life. The theoretical concept of parents acknowledging their emotional and mental wellbeing was a crucial factor in the challenges they face (see Figure 5).

Rosey was very forthcoming in expressing how she felt when she was told about her child's disability. She reminisced on the mere fact that she was single and had no support from her son's dad. She had no choice, but to cope and with some assistance from her mother, she was able to overcome some of the challenges she was faced with.

Actually, I felt really disappointed. Really shocked mostly. But I mean, devastated in our case because you know once anybody who is born, or getting pregnant, or having a child, they would love to have a healthy child. Knowing that the doctor declared that, that would have been mind-blowing for anybody. To learn that the child has been born with challenges. So that was devastating for me. The family suffered greatly, especially me. I actually suffered mentally and financially wise because there are certain things that need to be done and it couldn't have gotten done because of financial need. Furthermore, the father was not doing what he was supposed to do on the other hand to help, to pull through with the request of the doctors. So, that was another thing, plus I was working. I just gave birth, I was working, and he was born with a disability so that I could not say I go to look for a job. So I will have to stay in the situation and try my best to see how I can work with this. All right, in terms of emotions, as a mother, it will affect you emotionally because you want the best for your child. Also, seeing that what he's been going through is not what you want for your child, it is going to affect you. It's going to kind of. What's the word I should say? It's going to affect you in a way where it can. Well as I said, depression can creep in and stuff like that, but as a mother, to me, if we cannot properly emotion, not enough bad way but in a way where you don't want your child; to go through this but yet still you have to allow the doctors to do what they're supposed to do, I find myself in that position

numerous times when my son has been admitted at the Bustamante Hospital. Caregiving has affected me. It's affecting me a lot in terms of I don't have a social life. I dedicate all my time to my son. Three years. He's four now but he just turned four, so for the past almost four years, I dedicated my whole entire life through his in and out, ups and downs, I dedicate my whole time to him. I don't go out, I don't do anything other than just stay with me, and only him. Honestly, you just have to cope with it. You just have to work with your mental strength. You just have to refocus your mind and say this is it, it's you alone; if it is not you, it's mommy. They just have to cope until he passes the worst... I have to wait until he passes the worst, then I can resume having a social life but not at the stage where my child needs my time and my attention. I don't feel comfortable socializing right now while I know that he's at a critical part of his life right now. I would give that up until he passes the worst. Honestly, you just have to cope with it. You just have to work with your mental strength. You just have to refocus your mind and say this is it, it's you alone; if it is not you, it's mommy. They just have to cope until he passes the worst.

Kay stated that she and her family felt bad when they were told her son had a developmental disability.

I feel bad.... They feel bad, too... Because he won't talk and he's not going to school. sometimes I don't really cry, but I just wonder if he is going to walk and talk. I don't get to go anywhere.

Shay mentioned that she was never told that her child had a disability, but when she spent time with her nieces and nephews, she realized that there was something wrong with her daughter. Shay's daughter's father is very involved in their daughter's life, and according to Shay, her daughter's disability does not affect her as much due to her dad's involvement.

The doctor never told me.... I don't think it really upset me that much. That's not what I planned for, but I can't do anything more about it. Honestly, her father is around, so it doesn't really affect me. It's easier for her, also me, so it doesn't really affect me that much. If he wasn't around, it would affect me, he is there for her. She doesn't affect me at all. Anywhere I am going, I take her. I let everyone know that she is a special child. Anywhere I am going, she is special, we can go and party and have to carry her about. We try not to put in our heads that something is wrong with her. We have it in our heads that she is special. From when she was born, we try to work with it. I used to cry at one point, yes... but it's just one of those things.

Joy expressed that her family felt hurt and very bad at first because she never had to deal with anything of this magnitude before.

It hurt bad. I felt very bad... Because I don't know how to cope with it. I've never had to deal with anything like that before. My family "felt away" at first but they are getting used to it. Mentally, it's difficult...I can't work as I would want to. I have to stay home with him and I don't get to do anything or go anywhere. Sometimes if I have to go anywhere, I have to take him with me.

Ms. Brown expressed that she loves children, but when she was told that her daughter had a developmental disability, she was very sad. The family has grown to love her and has treated her "normal."

I felt so bad, I started to cry. I was wondering how was I going to cope with her? It's been pretty good; we get to love her so much. We didn't treat her in any way differently. We treat her normally just like the rest. No. We are really not affected, we mostly only go to church. I'm coping okay, because she mostly acts normal, like a normal child. Down syndrome only affects her speech.

Pinky spoke about how excited she was when she found out that she was pregnant. She wanted the gender to be a surprise and opted not to have an ultrasound. She expressed that when she was told about her daughters' disability, she felt numb.

All right, to be honest, I felt numb. The reason I was numb, it was my first child and I wasn't expecting that because one, I did not do an ultrasound. So, I wanted to be surprised at the gender. And then I got surprised with something else, which was...so, I'm not sure how I felt. It was like I had mixed feelings. It really affects me and my mommy because her father is not really around. For the entire year, he would call sometimes. He's not in a stable job. This moment he's working, next moment he's not. I don't really get that support and help from him. Emotionally, I have to be strong at all times. Sometimes I cannot hold it, I just break down. And then when I look back on how far she has come, I just say, "Lord, I knew I can do this. And you're not going to give me more than what I can bear." So, I keep most of it to myself. And the fact that she's a happy child, that's kind of keeps me going, as she's always happy. And to know that I am the reason for her happiness, I just decide I cannot disappoint her. Caring for her has definitely affected my social life... because as I said, it's my mommy and my personal family. If I'm supposed to go to work or anywhere, they will assist in caring for her. Oh Lord, coping is just hard. I wouldn't say it is easy. Really, it is hard and the fact that I'm young, sometimes I'll ask God. Well, I used to ask God, "Why me?" But then, I remember how strong I am. So sometimes I say probably because he knows how strong I am, he gives me her. Because probably for someone else, probably they would give her up or even try to hurt her or stuff like that. But I just try to do the right thing and do what I have to do for her.

George admitted his disappointment when he was told that his son has a developmental disability. He expressed his unconditional love for his son, but emotionally, he is concerned about his future.

Well, I felt disappointed when I heard that news. To be honest, my family, my immediate family, accepted the child and love him... my family love him and accepted him the same. To be honest, it affects me, emotionally... yes, sometimes. Sometimes when I look at him and I cry sometimes, and I tell myself when I look at him and I wonder why, but then again, I said, "The Lord must have a reason why he came into my life." Sometimes when I realize that it's kind of difficult for him to manage sometimes. I think what's going to happen when he becomes older, and honestly, sometimes it chews me up, emotionally. Mentally, I am not affected to a great extent. As I said, I condition my mind, I condition my mind and I decided to see whatever it costs, to face it, For him to feel loved and be loved and so I have to show him, love. Certainly not, I don't get to hang out as I did before. I don't get to go to parties like I used to, and I have to adjust myself and realize that I can't do some of the things I used to do. So I spend most of my time with him. And while other people at a party are having fun, I have to be by his side, constantly caring for him. One of the things that really help me to cope since he was born... on the second day, I started taking him to Bustamante Hospital for Children.... honestly, I can say, again, and my first experience when I saw him, I was disappointed, I was thinking all kind of things, but when I visited Bustamante Hospital for Children and when I saw some of the children, I had to thank God for my child. Some of the other children with disabilities can't walk, they can't talk. someone has to be doing everything for them, so I'm grateful for my child. So I use that reason as a steppingstone and a reason to give thanks to the Lord. He can talk, and he can walk and he is very, very smart.

Simone shared her mixture of emotions when she was told that her twin boys were diagnosed with a disability. She emphasized that it was not one child, but two children with a disability.

I was devastated. It was a mixture of emotions. I was confused, I was sad, it was overwhelming. I don't know, you just have this overall feeling like you did something wrong. I don't know if you can explain that, but it's kind of felt like maybe I am at fault; I'm the reason why they're like this. It was just the frustration, it was sadness. I think I had a little minute of depression going on there for a while about the whole situation. I was just devastated. I mean, you are pregnant, then you're having twins, and there's a joy that surrounds you with that. And then you see them grow up, and then it changes. So, you question the behavior. And then when you get something concrete and you're told, "Oh, it's

autism." You're not sure how to remedy that." So, I would say it was a mixture of emotions.... It did. And I can speak personally if you say that it actually separated me and their father. If that's a major thing. Because you could use it as an excuse, I don't know... but I don't think he dealt with it the same way I did. And there's the stigma attached to autism in Jamaica, and there is a lot of ignorance that's surrounding the disability. And as a man, I'm not making any excuses for him, certainly not, but I think he did not know how to deal with it, and it drove a rift through the relationship. So, pretty much as soon as we got that diagnosis, it was just downhill from there. He stopped seeing them for a long time, he never came around. It was that bad. It was almost as though he put them to the side. It's like, "That's not my children." That's the kind of attitude that he had toward them. So, yeah, it was a big change in terms of it affecting us. Yeah. They never saw their father for a couple of years, to tell you the truth. Well, how it affects me emotionally and mentally, people say that you are stronger than you have to be. Just with being with them the type of behaviors that they display. But... I don't think I am all that strong. I think where I'm at now is not where I was when they were diagnosed. I can say that. What I would say is that now I'm now in a better mental state than I was years ago. And I would say that it contributed by just trying to be educated a little bit more. It's an inside thing. Tolerance and patience, I did not know I had. It is a conscious decision that I have to do the best that I can for them. In Jamaica, some people say, "if your kids passed the worst," and that's a constant thing that I want to do. So even though there are challenges that I feel draining, physically and emotionally, to be with them and give the best and everything, it's in the back of my mind, I am doing this, because, if tomorrow comes and I'm gone, I'm trying to leave children that are self-dependent, and they can take care of themselves. I'm trying to give them the best education that their minds will allow them to process, so that they can be productive and normal, so to speak, members of society. So yes, it affects me mentally, but as I said, I'm in a way better condition mentally now than I was six years ago... Yeah. Well, I'm not a party person, generally. I am not old, but I am not. That's not my thing. I mean, to go out, yes I can, because they have a nanny. Because I do try to make time for myself. I think that is important. I'm not a party person, but where I can get a day by myself to go to the beach.... I take it and I leave them because I need to take care of my mental health. So, I can go out if I want to, but I'm more of an inside person, anyway. But there are times when I need a break, and I am not afraid to take it.... No. Once, I joined the Jamaica Autism Support Group. But to be honest with you, it's not something that I like doing, as in going into the meetings. I don't know. Maybe I don't like to dwell on the issue. To me, it wasn't so much support for me, personally. Not saying that it's not a good support system, but for me, it was more about. I'm reminded all the time. Do you know? You are busy hearing their struggles and needs. But for me, that made me more disturbed than happy. If that makes any sense. I didn't get the therapy that I needed to get from the group. But, generally, if I don't go to the beach, I'm occupied with going to school I mean, at work. Sometimes I just go for a walk, and I will take them with me if I'm going to a park or something. But, as I said, I'm an inside person. So, if I'm inside, I'm either reading something or... But,

yeah, that's me. I don't really go out.

June spoke about her daughter who was born premature and was discharged home early from the hospital. She expressed that her daughter did not have a disability when she was discharged home, but when she arrived home, her daughter stopped eating, stop moving, and just kept staring. She took her back to the doctors and after a Magnetic Resonance Imaging (MRI), she was told that her daughter had a cyst on the brain and later that she has cerebral palsy.

At first, I felt...it was like I cried day and night because I was upset. I was disappointed at a lot of things, I was just depressed. It was very challenging. Basically, on my side, because I am the mother. So basically, my life changed drastically. I had to be back and forth from the hospital, can't work, and whenever I try, even when she was bigger, whenever I try to take her to daycare, she's not eating. I have to bring her a bottle because they were saying she was falling into depression and all of that...so, it was very challenging. Emotionally, sometimes when you look at other kids and even other kids that are younger than her and doing stuff that you would think that she's the one and she's supposed to be doing. Sometimes, you just "feel away." Sometimes, you would get upset because of the fact.... because at first, I want to put her down on the mat, she just sat there, she doesn't try to move, she doesn't crawl, she doesn't do anything and even when she was creeping, she was just enjoying her bottom. No, I don't get to party and where family is concerned, it was just her father from her father's side. I don't think I get the support I was supposed to get from the grandmother and support on her dad's side, but I got full support on my side. On her side, it was just her father, and then at two years old, her father migrated. All right. As I said before, it is challenging... but now having her for three years, it has come like nothing now because she's moving around even before she starts walking. All right. She's a child-like this too, sometimes you will see her jump, sometimes she just put a smile on your face.

Wendy discussed that she suspected that her granddaughter had a disability before she was diagnosed as she presented all the signs and symptoms. She expressed that she wasn't feeling as sad but felt depressed at times.

I feel somewhat, not too sad, but... I feel sort of, I don't know what to say now. Depressed at times, knowing that I don't know what the future will hold for her. Well, the first instant, they wanted to hide the make it discrete. I became emotional in the first instance but not again. My family was not really affected one way or the other. Honestly, I cope. I don't know if it's because I'm experienced and I'm an early childhood teacher, but I cope well, really well, because she really listens to me more than anybody else. I don't

know if it's because sometimes I have a stage that when it's time to do things, and when she's doing anything and she sees that face, she just will say...when she looks at my face and see that expression, she will say, "Jesus."

Mother Hen who has some health issues of her own spoke about the different emotions that she feels at times. She is also caring for her mother who has a disability and is visually impaired. Mother Hen mentioned throughout the interview that God is seeing her through the frustration and the sadness.

Well, I feel sad and disappointed, but God knows everything best. He is small for his age, some of the children who are younger than him grow past him, so that makes me "feel away" sometimes. It really concerns me.... But God knows best. Sometimes I compare him with other kids and what he should be doing, but I just thank God for what he is doing, because some are not doing anything. It has been so frustrating, sometimes it's the grace of God that keeps me. Sometimes I get so down...I wish things would change or work out better. I don't get to go anywhere that often...and if I do go anywhere, I can't stay long. I can't leave him with anybody...it's like I have two babies at home; my mother is disabled and visually impaired. I don't do anything for myself; the only fun I have is playing games on my phone and watch movies sometimes. I used to go to church, but since the coronavirus, I don't go anymore.

Evelyn, like most of the parents raising a child with a DD, expressed the stress of the realization that her daughter is getting older.

I was shocked, devastated, and sad. Depressed after a while. Okay, well, it's been complicated, because when we are out in a rush, everybody to go out, there's a delay there in helping her. And it's a challenge with helping her because you have to do, obviously, kind of everything for her. She's nine years old. She will do self feeds, but she causes a mess. So she will feed herself but she causes a mess. She will put on her clothes, but she takes long, and to do any other thing, you have to be at her, and it's really rough. It's a challenge. So sometimes the noise, she makes a lot of noise. And my son sometimes has to study and affects him like there. And then sometimes when he has to step aside to feeding time for her when it's his time, that also affects him. We try to cope even though it's hard, but we do a lot of prayers that at the end of the day we will achieve something. That will come through for her. So there are challenges there.... It's a setback. And yeah, sometimes as you said, it will get better. That's bad, but you get used to it because she's your child... I like caring for her naturally. So, I thought it was hard because I have to take her to work with me, but we try and cope. Oh, well, well. Yes. Well, that's even extreme right there because that can be very. and sometimes I

feel a bit bad and especially when you think and she's aware. She's getting older and you're not getting younger because I'm almost middle age, and it's a bit stressful with her in that aspect because you have to always give her your full attention. So, sometimes, it can get hard, but I try to work myself out of it for her... You're stressed out and I know that it will get better over a period of time. And I assist her because she doesn't do it fully. And brushing her teeth, she doesn't do that. So, something I have to help her with it. So, we try. we do our best... this is it. So, this is what we have to do. So, we try and cope. She knows that she has to take a bath....so we assist her. We don't let her get the best of us even more. We are Christians, so we don't go to parties. We go to church. Not saying that parties are bad, but we are indoor people.

Sandy unlike some of the other parents raising a child with a developmental disability, denied having any emotional feelings when she was told her son had a disability. However, she expressed feeling sad at times now that he is growing up.

Oh, I have to just work with it.... Because I went to a meeting by his school and explained that sometimes you are in Jamaica and take a flight to the UK and then you end up in the Bahamas, and you plan to have a nice healthy baby and they come this way you just have to love them the same. We just have to accept it; some people don't want to accept it. He did not walk until he was 3 years old. I had to take him to a children's hospital. They were going to cut it off and put an iron in it. Yeah, a little sad at times, and whenever he sees that he come and sits with me, but for the most part, I am good. Some people say they would not keep him. I don't have a social life. I don't get to do anything or go anywhere. I just don't leave him. If I have something important to do, I would be gone for only a couple of hours. No time for anything else. Sometimes if I have the time, I will sit... I'll just do some puzzles.

Crystal expressed concerns about her brother's future in society and how he would be treated as a person with a developmental disability.

I was shocked. And I will say I was sad, thinking of problems in the future that he would have, struggling in society, or being bullied. I wouldn't say that we are affected because we accept him the way is, we understand him.... We treat him just as we treat everybody else. Emotionally, yes. When we go out and someone tries to speak to him, he's always nodding and saying, "Yes." But some of the time, I know that it's because he didn't hear what they said and he didn't want to prolong the conversation. So I feel bad that he can't communicate the way he wants to... or hear.... I'm getting teary now. I wouldn't say caring for him it's affecting us really because everyone loves him. Everyone treats him normal or they try to learn sign language. They ask him stuff and they tell him to show them what it is in sign language. It's very good that all my friends, they love him and

everyone that's around, they think he's so sweet. Always saying, "Oh, he's so cute." And stuff like that. So I wouldn't say it's affected pretty much anything. Just accept the way he is. I wasn't even that type of person to go out or to party. So, no... but If I ever want to go out, yes, I can go out because I have my friends that will babysit him for me if I have to go somewhere.

Keva discussed the hurt and shame she felt when was told that her son had a disability.

She expressed that the challenge is not only his disability but all his other medical conditions.

I was crushed, because it's not only the disability, because there was more than one problem, so I was hurt. I felt bad. Just thinking it should be good at the time, just having him, seeing him, yeah? It's hard because the thing is it's not only the disability that's the challenge. It's other medical conditions. It was really hard to believe. So I think it's because I don't have enough yet. At first, I felt ashamed...I did. It does. Emotionally, mentally it does because, to be honest, every time you have him, people just keep looking, their face, they are saAs I said, it gets easier, To be honest, it was hard to cope but then what happened...when he goes to Bustamante Children's Hospital, where other kids are worst...it would be a different feeling. When I had him, I was afraid and for him to walk . he just slows everything down. Not mentally, but physically couldn't . the walking, the creeping, he'll do everything differently. And when I take him to Bustamante Children's Hospital, you'll see other kids that they can't walk at all and I said...there is hope. To be honest with you, I don't do much for myself either; I go to work and church and I also have some health issues myself.

Brenda spoke about her depression when she was first told that her daughter had a developmental disability. She has strong family support, and caring for her daughter now is not as strenuous.

Well, I was depressed at first. I used to cry a lot about it. At first, it was kind of stressful for everybody, but we eventually learned how to cope with it. Well, at times, I used to cry very much. It was kind of strenuous because most things you have to do for her. You don't get time to actually do what you want to do for yourself so...you have to invest more of your time in her. So, it kind of makes you feel depressed. It kind of makes me feel very depressed, and sometimes I will cry about it still. Or I would probably go somewhere to relax my mind from all of what was happening...No...well, I didn't get to go out a lot...I did not like going out before, but even with that minimal social life that I had, I had to hold back on it. My family wasn't really affected because my mom doesn't work with anybody, so she really makes time for her and stuff like that. Probably like to go to the beach just to relax. That was at first, but not anymore. She is more mature and she can help herself more.

Birdie spoke about the challenges as a single mother caring for her son with a disability and her young daughter. She is the sole provider for both children and gets very emotional at times.

It's the first I was hearing about the sickness, so it was about . he didn't look anyway to me. He looks like a normal child to me. While he was growing, he looks like a normal child. I get emotional quite a lot now because I am a single parent and just me and my daughter, we all live together. It's three of us...it's rough on me sometimes. I have to prepare for both of them. I have to encounter his disability to help him around. I need to care for him and can't leave him alone. Sometimes there is a good job also, but I cannot take it because it's just me and him and my daughter. My daughter is very young. So that becomes another stress. I just have to cope with it; there is nothing I can do about the situation. I don't get to do anything, like I mentioned before, it's only the three of us. Well, if he is comfortable...he is ok whenever. All right, he loves to watch TV and from the moment he has his TV or tablet, he is comfortable, I have no problem...I can sit down and relax a little, maybe watch the news or something.

Shelly spoke about her strong family network and the adjustments she had to make as a mother. She expressed that her mental and emotional state made her stronger than she thought. As a result of her newfound strength, she was able to restore her "best health."

I guess initially when you heard not knowing much about that whole area, it didn't really hit you right away as to what the challenges would have been. And at the time being that he was a newborn, you wouldn't have known exactly what the disability would have been, but cerebral palsy is a wide spectrum and it could have been a number of things. And in his case, there were a lot of things going on because he was pretty much premature at the time. So, as he got older, then you started to see what exactly was the challenge was when that became the issue where you're taking a baby to physiotherapy. Prior to starting physiotherapy, there was a period of denial there, that there was no need for that, he's going to eventually be able to do everything. So yeah. I'm not sure if it's affected our family in any way really. I mean, we have another child and once you start having children, your whole social scene gets changed because you don't exactly just get up and just go anywhere. I'm not just husband and wife, but there's a child in the mix, especially with a young child, there's not much going out. If you're going out, you probably leave the kids with family or friends and you go somewhere, but you're not necessarily overnighing or anything. For us, we have a pretty good solid family network, so when schools are out and holidays set in, they're usually with the grandparents. And so, we get that break. In terms of how it has affected our family, personally, it's just one of those things that nobody plans for that... but know that it is a part of your life. You have to adjust and the quicker you

adjust to it, the better everything will be for you. Because as much as it is not ideal, you know that you have to get over whatever feeling you're going through because however you're feeling, that's not going to change the situation. And so, you immediately have to start to put things in place as to how you're going to deal with this new scenario in your life. It has its ups and downs. That plus everything in life impacts you. I can't say for certain that my emotional health has been impacted by any one thing such as having a special needs child. Don't want to say it's because that while some of it may have impacted me emotionally and mentally it also showed me I was stronger than I thought by being able to manage all of it and to fight my way back to my best health. Other things, for example, my dad was diagnosed with multiple vessel heart disease and needed a quadruple bypass almost immediately. I furthered my studies. Thought that would kill me. If I sat and thought it all through, I could list more. All in all, my mental health path was decided by one thought. Well, I have already adjusted in my head that there's only so much I can do. And I don't push myself to the point where I am telling myself that this has to be that way or things have to be a particular way. For me, it is what it is. I read something once where a person was talking about a parent juggling balls, and you're juggling so many things and you don't think that you can drop anything, but at some point, it is okay to drop some things and allow them to just fall to the floor and break. And you have to be okay with that. And so, for me, my balance is knowing what my limits are and that I can't take on too many things because I have to be able to be free if there's an emergency and I'm called for him, I should be able to move. But for me, what was balancing for me was when I went with something that was specific for me, that I was doing it just for me, not trying to do things for everybody else. But I went back to school and all of that higher learning was all just for me, wasn't doing it for anybody else. And I think when you have a life like this and there are so many things going on, you really have to find one thing that makes you feel like you have value, you're important. And at the end of the day, when you see the reward of it, it feels good for you and you feel that self-worth.

Keisha expressed being in denial when she was first told about her daughter's disability.

She discussed how caring for her daughter has affected her mentally, to the point where she has decided not to have another child.

Well, in the early years, I was in denial. When I used to take her to the clinic...each time I realized I was going much often than the norm. I was told that the child wasn't developing properly. They checked the milestone and referred me to an organization in May Pen. I didn't go because I didn't see anything wrong with her...and it's about four or five times I visited this clinic, and the nurse and the doctors keep saying...Mommy, you don't carry the child to the organization as yet. I keep finding excuses because I didn't want to go. So, that was my biggest thing...well, I was in denial. I was saying that nothing was wrong with her. Even then, she didn't look anywhere like she was ill or anything. Well, it's not both

parents because it's really on me...It's solely on me because her father had denied her. he has never owned her. I would say that mentally, it's affected me so badly that I can't even. It's like I'm...an example...like I was at work, and a coworker had a little baby, and she wanted to go to the bathroom...But because she's always here with me, she asked me if I can hold the baby for her. I told her no, I can't hold the baby. But she keeps saying, why, just hold him " I said, "No, I can't hold him." And I shouldn't have said....I guess she felt more comfortable with me holding the baby for her to use the restroom than any of the other workers. But I took the baby, and when I took the baby, I was scared, shaking like crazy. And I had this funny feeling, that must have looked like I want to kill everything. But I [inaudible 00:11:18]. It had affected me and it still affected me, because even when she came back from the restroom and then she took the baby, I went around the back, and I washed my hands from my palms up to my blouse sleeve. I wash it like I was trying to take off the scent of the baby and everything...So that's always affecting me mentally. And I tell myself then that I would never have another child, and I still have it in my mind. Persons told me that you don't have a husband, what if you get a husband and he wants a child. But from me, that will have to be a discussion with me and my husband. Mentally and emotionally, I will not be able to deal with it. I don't know if I would really carry a child again or what will happen after...emotionally I wouldn't be able to carry that child for nine months...If I would give the child up for adoption or what, that's how I feel. But I don't know if I explained how I am affected mentally. No, no. No. I don't get to do anything. It's just from work to home and to church, before COVID here, I did go to church on Sundays. But now I try to really go to online services because of COVID. It affects me and even there at work, every year the company pays for us to go on vacation for an entire weekend. And every year, I have to take care of her. Every year I take care of her. So it's even when they say, "Here, you take a break, here...now so you can just go and enjoy yourself." Every year I take her with me. Every year, I have to take her with me. And so, I don't get to go out to socialize, anywhere I am, I have to have her with me because she's 13 now, she will be 14 this month, and I can't trust anyone with her. Because she cannot explain herself, or if she's walking now and she's walked in the wall, or she hits her anywhere, she can't come here to mommy and she smacks the wall or hits my floor. So a bump in the wall, or a drop, she doesn't notice anything at all. So I can't let go of my guard, I have to just keep her. When I go to work, I have to pay someone to stay home with her. Well, there was one point where I had to seek counseling from my company, the company I work with, which provides counseling for family and so I signed up. So there are times when I go into counseling and that's the time when I break down. Also, when I go, she would advise me, "You know what you have to do; you have to go to spend a little time, you have to have a little me time." And all of that.

Molly feels sad about her son's disability. She worries about her child knowing that he is different from his friends.

At first, we did not think anything of it. The doctors did say that he would need

surgery, but in our minds, he would outgrow it. Then as he grew, it became worse and so we were devastated especially when we think of surgery. It has been hard, especially whenever he is admitted to the hospital. Going back and forth is no joke when you are unemployed. I can tell you that there were times when we had no clue how we would get to Kingston to see him. Caregiving has not affected me mentally; however emotionally, it's hard to explain. Sometimes when I am alone, I cry constantly. I sometimes worry about my son. He knows that he is different from his friends, although he attends the same school as they do. He sometimes gets embarrassed to wear his brace. That makes me very sad. It hasn't really affected my and social life that much. My child comes first. I usually don't go out that often, but if I have to, I will take him with me or his dad will care for him. I try to take it easy, no matter what. I take the time to read or to watch a good movie.

Pat spoke about how counseling has helped her and her family emotionally and mentally to understand her son who has a disability.

At first, I was shocked. But then I have to learn to live with it. Sometimes I was wondering why and how come. His disability affects us when he has to go to school...Especially with transportation. But otherwise, we learn to adjust to it. It will upset me because you know you want to go out to work and you can't work. Like you want to go to places like churches but sometimes you can't go because he's doesn't want to participate or doesn't want to attend certain functions. You have to monitor him 24/7. We don't do anything special...and now we can't go to church because of COVID. We learn to cope with it because we understand him and we used to go to counseling. We used to go to the University of the West Indies for counseling....The child guidance clinic. The counseling helped us a lot.

In summary, the theoretical concept of emotional and mental well-being was identified among all the participants. High levels of stress, depression, and other health effects were common among the parents/guardians raising children with an IDD. The identification of this concept is critical to the challenges they face and the basic social problem of lack of support and services.

Theoretical Construct: Professional Awareness

Parents or guardians raising children with an IDD in Jamaica expressed the lack of awareness of doctors and nurses of their child's disability. Some parents stated that doctors and nurses need to be aware of the different types of disabilities and how not to treat each disability

the same. Some parents also expressed the lack of empathy toward them and their child with an IDD and lack of information, resources, and education from doctors and nurses regarding their child's disability. Parents expressed that increased information, resources, and education would prepare them mentally and emotionally to care for their child with a developmental disability (see Figure 6).

Rosey spoke about the lack of empathy shown by doctors and nurses. She expressed the fear of leaving her son's bedside whenever he is hospitalized because she doesn't trust the care from the nurses. Rosey praises her son's neurologist for her care, commitment, and transparency to the parents who are raising children with an IDD. She also discussed bringing awareness to society, as this would help with the stigma and the lack of knowledge toward persons with an IDD.

Doctors and nurses. Doctors don't care. Nurses do not care at all. Only time nurses care unless they realize you have big bucks in your pocket or you drive a fancy car or you are fancy and nice. That's the only time they will care or they look at your child and they'll realize the child doesn't wear nice clothes...they don't care. Once it is that, they realize that your child wears nice clothes and KFC coming and Popeyes, Pizza Hut, or Domino's come in, you know that your child is getting the best treatment. When it comes on to the nurses, because I've experienced them for three years, they work with us [inaudible 00:33:38]. And once it is that, they realize you don't have certain things, they don't care. The child can be there crying, bawling, they care zero. Once it is that, they realize that you are some standard or you are a professional, or if not you have some amount of money to pay, they'll pay your child mind. So there's no empathy there? It's about what you can do. So that is what we do. My son's neurosurgeon, she's very straightforward and she's telling the truth exactly how it is. No sugarcoating, not anything. She comes out blunt. You see because of that, nurses don't like her because of what it is that she talks, that's what she means. Understand? So I mean she's the best one that I've seen thus far for the three years. Although she's the head surgeon for the kids there still, I mean, she's a good, good doctor, so we can always sit down and relate to her and she tells us exactly what to do.

Shay discussed the need for more training for nurses because of their attitude and the way they treat parents. She expressed that doctors need to perform more assessments and tests when a

baby is born so that parents are more prepared if the child is born with a developmental disability.

See the doctor now, they need to check more, pay more attention to when a baby is born or something. Run some tests to see if the child's special or whatever. We need them to put things in place. When a lady comes to give birth, do a checkup on the child first. Check on the child. We need to know what happens when the child is born so we don't have to go through so much. All right, some of the nurses don't know how to deal with people. Some of them, I feel like they are the reason why some of the babies are born like that. They treat people [badly]. They make some people leave, they need to deal with people better because some of them are ordinary people. I have my child there and see how they treat people. They make you afraid to go there...Because, of the way they treat people, babies will be born handicap or with disability or anything, because of how they treat people. A young girl, I was in the room at the same time when she is there. Tell the nurse that she was ready to have the baby, she goes on the bed and the nurse and the nurse told her that she is not ready, and then she said to the nurse, "Yes, nurse, I'm ready. I'm ready." The nurse told her to come off the bed. She's in pain. I was there lying down, and the nurse told her to come off that bed, the baby just dropped right out. They don't make you feel comfortable going down there. The girl told them the baby is coming. The nurse turned to her and said, "No." She said, "Come off of the bed." It's still in my head because all of them treat people like [badly]. They need to put up things in place down there, for the nurse to learn to talk to people and deal with people better. They need to change their ways down there. They need to put some more things in place because sometimes, the way some doctors pull the baby. Sometimes, it causes things to happen to that child. Some of them pull the baby. In ignorance, some of them slap your leg, you, and then the baby. They treat people like [badly]...better than that. They need to deal with people the way they want somebody to treat them. In the same way, when you have a baby yourself, you need that type of treatment. They don't need to deal with people like they're nobody when they come up there. You need to treat them like a human being to another human being, then you get better. They're adults, or they're not a child or something. You cannot deal with people like that. They need to train them down there. They talk to you anyway as if you are a child. They need to change their attitude.

Joy spoke about how children with disabilities are treated by doctors and nurses. She

expressed that they need to be loved and that doctors and nurses need to understand them more.

They have to know how to get along with them; some people don't treat them well. They rough them up. And sometimes they don't understand that they are children all over, they might be big in size. They are like babies, young babies coming up. They need tender loving care.

Pinky discussed the need for doctors and nurses to share information with parents raising children with developmental disabilities.

Well, they could give us a better understanding of the disability that our child or our children have. Because up to today, I don't really understand. I just know that she was born with a spinal disorder, that's it. I don't remember the name. I don't really get a full understanding and even ways or what to do to help her improve, other than some therapy. So I think they could do some more research, and when the child is born, they could sit us down and even provide us with some information or even have some printed information, so that could help us to help them better.

George expressed that doctors and nurses should talk with parents and be aware of the child's needs.

I think doctors and nurses should be aware of the child's needs. They should talk with the parents and with the child. If they can help with the child's physical abilities, and the child's mental abilities, if they can assess the child's physical and mental abilities, then I think they will be better able to assist in those areas, respectively.

Simone discussed the insensitivity of doctors and nurses toward children with developmental disabilities.

So, the biggest thing that we have here is that they're generally insensitive. I'm on my way to a doctor's office, with my son who is non-verbal. Not the doctor's office, an ophthalmologist. And I remember she called him up to read the letters. He's non-verbal, but he knows every word, and he knows a little of everything. So, when she called me up, I said, "He may not speak for you." Because they're telling them he will communicate, and then there are others saying he will not. And her comment to me was...How is he going to see the doctor if he can't say what he is seeing? Oh, Beg your pardon. How is he going to relay it to the doctor if he's not going to tell me the letters from outside before the visit? And saying, as a doctor and a nurse, you would have different types of patients who come in. Some will be verbal, some will be normal, some will be autistic. And so, you have to listen be sensitive to that, there must be alternatives. Because, if you are a trained professional, in my opinion, I don't know. If you are a trained professional, you must have been trained as an alternative. What if the person is dumb or deaf, or blind? Do you understand? How do you treat those people? They're the same thing. And I feel like everywhere I go, in order to not be treated so insensitively, I have to explain to people, "They're autistic. So, if you could just excuse them from this ." or excuse them from that, or excuse them from doing this. Because you don't want them to be treated any less

than any other patient. So, it's very insensitive, and it hurts you. It's what we go through here all the time. The number of nurses who are caring, and love their job, and love people, is way less than the number of those here who just go to work every day, because... and that is in the public system and private system as well.

June expressed the need for doctors and nurses to be more educated on the different types of disabilities and that they should not assume that all disabilities are the same.

Well, from basically since she has another disability and going and going to the doctors- all right. Basically, I think that being a doctor and being with a disabled child, it's kind of hard because you be with more than one kid daily. But being with a disabled child you have to read and get to the bottom of what has been happening to the child. The reason why I said this when she did her surgery at Antabuse Hospital, she had twitching one. It wasn't a major seizure one and from that, she was six months, then from that, she didn't have any episode of seizure. And after she did the surgery, the doctor there put her on Baclofen. When they put her on Baclofen when I came, in the night she had a seizure episode in the morning she and I had an episode of a seizure again. I lost the skin when I came to, and I had to pick her up there and when I go on the internet and read the medication, the side effect was it can cause a seizure. When we went back there, they took her off the medication immediately, so it caused that. I'm saying now that doctors have to be more careful when they are dealing with a child with special needs. Right. And sometimes too, you have to ask the parents questions, like big into questions, ask questions and what ...because not because you're a doctor, that doesn't mean that they're going to know everything about my child. I have my child day in and day out, so I will know more about my child than even you. Because you will see the child and because the child is lying down in my lap, people don't know the child can't stand...because I have the child in my hand, you don't know that she can't walk. So sometimes it is good to ask questions and don't assume, oh I know. No, not because the child has cerebral palsy, you might be with ten children with cerebral, doesn't mean that the tenth child has the same abilities or can do the same thing because all of them have the same diagnosis.

Evelyn, like some other parents, discussed the need for doctors and nurses not to assume what is happening to her daughter with a developmental disability. She expressed the need for doctors and nurses to take the time to examine these children with disabilities.

They assume a lot because of her behavior when she goes to the doctor. They just listen to what you have to say because they don't want to get her irritated. So, they're just like, "Okay, okay, okay, don't bother." Like for instance, I take her there and I'll say "sit down" and she starts crying because she has a phobia of doctor-This happened because she won't allow them to look after her because she has that fear. So, I have a feeling that she keeps crying and she shows me her head and says

hot...I must code it because she doesn't give them a sentence. Just one word...And then they will be...ok, maybe it's something she eats...or an allergy. They assume, right...Because they cannot check her health because she is not allowing you to do that. I want more for children with disabilities because as you know, that here, especially in Jamaica., they do not highly acknowledge disability, it's just recently things started popping out. What I would like, more attention from them and more... More awareness.

Sandy spoke about the need to tell doctors and nurses how to treat her son with a developmental disability and the fear of ill-treatment if she leaves him in anyone's care.

Yes, when I go in there I tell them how to treat him. Because some of them are rough. I make sure they know that he is autistic. He also has epilepsy... And I don't leave him anywhere because I don't want anyone to ill-treat him. People don't understand him.

Crystal spoke about the need for doctors and nurses to be educated in sign language to improve communication with children with developmental disabilities who are not able to communicate.

I think that in medical school, overall, our doctors should at least know basic sign language because if your child goes to the doctor and a parent isn't with them or a schoolteacher or some caregiver's there to translate, they're completely clueless to what the child is experiencing. They have no knowledge of what is going on, what they're trying to say, or where they're feeling the pain. They should at least learn basic sign language because it is a language Just as how they're taught Spanish in school, how they're taught, French. I think sign language should be learned and learned worldwide because they do exist in our world and they are a part of our communities. So it would be good if we can even just communicate a little with them and not let them feel so alone or like strangers or like they live in a different world. I would like to say before I had my brother with this disability, I've always looked out for persons with disabilities, care for them, defend them if I have to, because I think it's not their fault that they were born like that. People tend to be very cruel toward them sometimes, and they don't have people to defend them. For me, finding myself with a disabled brother, basically, I had a mental state already to give care for him or to love him the way he is and defend him. Maybe that's why he was always drawn to me from birth because even when my mother is here, he's always around me

Keva discussed how difficult it is for doctors and nurses in Jamaica to care for children with disabilities.

To be honest, I don't know how doctors and nurses...I know their job is hard, but caring for somebody with a disability, I don't know how they view it because, for the parent itself, it's really hard...They're looking to the parents for answers.

Brenda spoke of the need for information sharing and understanding in doctors and nurses toward parents who are raising children with an IDD.

That's definitely true, some of them are not. Because I remember this one time, I had an incident with my doctor. When my daughter was smaller, she hit a lot because she couldn't speak so that's how she learned to express herself. This lady was a nurse...a practical nurse...And she hit the lady, and the lady pinched her.... And I was so upset because she was smaller, she couldn't talk. I know that she was probably trying to get her attention and she hit her...And she pinches her because a lot of them don't understand that when someone cannot talk, they use whatever reaction they can to get your attention. They should actually help parents more and inform us more because most of the information that I received I actually got over the internet. It was not given to me by a doctor or a nurse. I got most of it from over the internet. They actually didn't give us any awareness...They don't have any brochure, anything that you can take home and read and understand how to deal with the development of these kids. It's very minimal. We have to actually go to the disability foundation...and it's all the way in Kingston and not every parent who lives in Kingston has access to that. I recently just found out about this place...not a long time ago, there was another parent who had a child with a disability that brought me here. Places like these are tucked away in Kingston and not widespread over Jamaica, and so I think this is how doctors and nurses would fit in.

Shelly spoke about the assumptions that doctors and nurses make that parents have an understanding of their child's disability.

Well, I don't know about the school-aged part, but I think for me when we were first told exactly what's happening with him, there is this assumption that when they speak, you understand. They're the doctors, you have never heard of some of these things before. Just calling it by name doesn't really say much. And then it's so wide that you're not sure what to do, where to go from there. I remember when we finally got him home from the hospital, we were told that we had to make frequent visits to the eye clinic at the hospital. And there were just so many clinics that we were going to that it was just too much. We had to get to a hearing clinic, we had to get to the pediatric clinic, premature babies clinic. There was the new neurology clinic. There were so many different things happening and you're still expected to be at work. So, one of them got dropped. We weren't doing the eye clinic and it was after a couple of weeks, somebody said, "Have you been to the eye clinic?" I said, "No, I can't do it anymore." And they said, "No, you definitely need to." Turns out he was developing something called retinopathy of prematurity, which is something that can lead to blindness. There's nobody there to

really guide you. But of course, this is a third-world country and doctors have this notion, I think, that once they have done their part, they've done their part. And so, they're just moving on to the next case. There is no personal touch, so to speak, and nobody there to follow up. I have heard some horror stories there. Molly and Pat discussed that doctors and nurses need to show empathy and compassion.

They expressed that they need to understand the challenges that parents experienced in raising a child with an IDD.

Doctors and nurses should have more patience and be more respectful. They should also be aware that we don't always understand what they are telling us. In other words, show some empathy and compassion. They have no idea what it is like to care for a child with a disability...Doctors and nurses...need to be more educated about the disability and the challenge that parents have and children. The last time...The last time I went to the doctor with my son, his doctor was there and my son touches a lot...He touches a lot. And she was like, "Hold him. Don't let him touch me. Don't let him touch me... Don't let him touch me." So sometimes I think these doctors are unaware of the symptoms or the side effects that come with the disabilities. I think they should identify the problem and see what disabilities children go through? Because it's also embarrassing when you go out with your child, and a doctor pushes him off and said, "Okay don't come too close me with that child because I am scared of him." And stuff like that...

In summary, the construct of *professional awareness* was identified throughout the data.

Parents and guardians indicated the doctors and nurses need more education on the different types of disabilities to be able to care for their children with an IDD. If nurses and doctors get the education that's needed to understand children with IDD, they will be able to care for them with compassion and empathy.

Theoretical Construct: Stigma

There were concerns about the stigma in Jamaica toward children with a disability.

Persons in Jamaica still stare and say negative words toward persons with a disability living in Jamaica according to many of the parents throughout the interview. Many parents expressed fear of their child's future and how they will be treated by society. These concerns have caused stress, depression, anxiety, sadness, and other health issues among parents and guardians raising

their children with an IDD (see Figure 7).

Rosey spoke about the stigma and bullying that children with disabilities face in Jamaica. She expressed that stigma and bullying are the results of a lack of knowledge and understanding of the disabilities from some persons of society.

Because Jamaica stigmatizes a lot. They tease and bully a lot. Once it is that they see a child but that child's head is just a bit bigger than the normal size, they tend to tease, they tend to bully because of the lack of knowledge. Understand? Just like a person knows about sickle cell versus a person who knows about diabetes, persons know about down syndrome, persons know about autism, persons know about whatever, asthma, chronic health disease, heart conditions, what persons are not aware of hydrocephalus in generally.

George spoke about how people laugh and look at his son with disgust when he is on the streets.

They were looking disgustfully at my son, but that doesn't bother me now. That was the way he was born, so I loved him, and I accept the baby just the same. And my family loves him and accepts him the same when I'm on the streets.... and I could see like some persons really laughing.

Simone described the stigma that still affects children with disabilities. She also stated that the stigma in Jamaica could be the reason for her children's father not being involved in raising their twin boys with autism.

.... And there's the stigma attached to autism in Jamaica, and there is a lot of ignorance that's surrounding the disability. And as a man, I'm not making any excuses for him, certainly not, but I think he did not know how to deal with it, and it drove a rift through the relationship. So, pretty much as soon as we got that diagnosis, it was just downhill from there. He stopped seeing them for a long time, he never came around. It was that bad. It was almost as though he put them to the side. It's like, "That's not my children. That's the kind of attitude that he had toward them. So, yeah, it was a big change in terms of it affecting us. Yeah. They never saw their father for a couple of years, to tell you the truth. I'd like to say that I'm a very open person, and I like to speak honestly about these things. Because I feel like having children with autism or any disability, I feel like if you express how you really feel, people have a tendency to look at it like you're a bad parent. If that makes any sense to you.

June expressed the need for some Jamaicans to educate themselves on children with a disability. She also shared the lack of government involvement in educating the public

about children with disabilities.

In Jamaica, I don't think the government really highlights overall children with special needs...we should get away from the stigma. To know that they are just different. They may not be able to do the things that some kids can do, but they're just different, that doesn't mean they're less. YouTube is there, the internet is there where you can educate yourself....you know? But I think we need to get more awareness.

Evelyn., like many of the parents has asked for the public to be educated on persons with a disability

....More awareness... And for them to be treated because sometimes when we go out with her, people look at you one way and some will laugh sometime at her behavior and when you go to a strange place that people are not aware of her disability... there will be people staring at the child... stare, you know? And you feel very uncomfortable. So that's why they look and laugh... they are not educated. And even adults do it. You say, "Well, that's a child or a young person." But adults, it's like, wow.

Crystal felt that people should be mindful of what they say and how to treat them, as these children can read body language and can tell when someone is rude.

I think a person should be more mindful of what they say to them, how they treat them because even if they cannot hear, they can read your lips. So if you say something insulting to them, they can understand. And just by your body language. They're taught to study body language, so they might not know what you're saying, but based on your body language, they know that it's something rude. And they also have feelings. I think people should be more mindful of what they say to them and how they behave around them because they are human beings and they have feelings. And if they take the time out to get to know them, they'll realize that it's a very beautiful community.

Keva expressed the need for adequate promotion of persons with disabilities and for dialogue to take place.

Emotionally, mentally it does because, to be honest, every time you have him, people just keep looking, their face, they are sad. To be honest, one time I remember taking him to one of his appointments. There was this lady and she was just staring at him and then she starts to look and she said, is the handicapped, and I, to be honest, I did feel bad. I'm thinking, just because I'm...I was ashamed. I

realize that he's different, but in Jamaica, I don't think they're getting it. I don't think there is enough promotion, there are enough people talking about it, trying to deal with it better so we look at it differently. It's not a handicap, it's a disability, doesn't mean that your life ends or you can't be anybody you want to be.

Brenda spoke about the lack of awareness of stigma and treatment toward children with a disability.

I think lots of persons are not aware of these things...the disabilities, they don't know how to deal with them. A lot of persons still ill-treat these kids. If it's very minimal in awareness, you only have a few individuals that really care and show support for these parents. I've been verbally disrespected by persons because of my daughter...Multiple times, It's not one, not two times, but persons who understand...that doesn't mean that you don't love them. They tend to put a stigma on it, and they tend to look down on that child as if...

Shelly has observed ignorance among certain low-income communities in Jamaica, their knowledge base, and their action toward persons with a disability.

I've not really been exposed to it. If there are, they're probably not doing it to my face, which is possible because persons have a tendency to talk but not in your hearing when they're talking about you or your child, but I've heard some really terrible things. And I think the biggest issue is probably from low-income areas, communities, worst side of Jamaica, where persons just are really ignorant to certain disabilities. Well, it's not even just disabilities, it's mental health. Anything in Jamaica where people just don't understand, there is that behavior toward it that's very standoffish or rude kind of position that is taken toward the individual. For disabilities, there is heavy bullying. I think my child is also still very young. He goes to a school with kids just like him, so we're not exposed to that.

Summary of Findings

In this chapter, a concrete theory has been introduced that identifies, describes, and helps to explain the experiences and challenges of parents caring for children with an IDD living in Jamaica. Lack of support and services is the basic social problem experienced by parents raising their children with an IDD. The core concept of their challenges and experiences has been identified as *the challenges they face*.

Parents face many challenges in raising their children with an IDD during the different

stages of their lives. Based on the data from the interviews, it is evident that the core concept of *the challenges they face* explained their experiences and difficulties in raising their child with an IDD. During data analysis and insights achieved from constant comparative analysis, the core concept occurred in the data with other categories and theoretical constructs connected and attached to the main core. The core concept of *the challenges they face* is the central idea that emerged from the data and is able to explain variation in the information. This core concept illuminated a concrete theory that describes and helps to explain the phenomenon of the experiences and challenges of parents raising children with a developmental disability and was obtained from theoretical constructs that were grounded in the data. Five theoretical constructs are associated with the identification of the challenges they faced: burden, it's challenging, emotional and mental well-being, professional awareness, and social stigma. The major theoretical and subcategories are outlined in Figures 1-7.

Parents raising children with developmental disabilities expressed a great deal of financial burden, mostly due to their marital status and unemployment. Some were concerned with the child becoming a “burden” to others, while others are faced with the burden of guilt and mistrust. These recognitions and concerns help in the identification of the challenges they face.

Parents recognized the challenges in raising their child with a developmental disability. Some expressed that raising their child with a disability was not really a burden to them, but they said “It is challenging.” As the child grew older, some parents became more concerned with their child’s future and need, and that the child might become a burden to others when they are no longer able to care for the child.

The emotional and mental well-being of the parents played a pivotal role in raising their

child with a disability. Parents expressed their emotional and mental state using words such as *stress*, *depression*, *hurt*, and *shock*. Parents need information explaining the types of disability and how to care for their child with an IDD in order to manage the daily stressor of caring for their child with an IDD. Some parents expressed that their faith in God has guided them through their emotional and mental wellbeing in raising their child with an IDD.

The need for professional awareness was a common theme throughout the participants' interviews. Doctors and nurses should educate, communicate, inform, and support parents raising children with an IDD. There is also a need to educate society on the social stigma against persons with disabilities. It was identified that there is a need to educate society on social stigma against persons with disabilities. It was identified that persons with disabilities are not highly regarded in Jamaica. They are laughed at, bullied, stared at, jeered, and at times, parents are insulted.

A concrete theory was developed focusing on the essence of many case instances interpreted in the data in a parsimonious relational structure. The constructs of Burden, It's Challenging, Emotional and Mental Well-Being, Professional Awareness, and Social Stigma was a common theme in all participants. These constructs were used to identify the challenges they face. The constructs and associate strategies were employed to identify the experiences and challenges of parents in raising a child with an IDD in Jamaica. Lack of support and services was identified as the basic social problem.

Figure 3: Theoretical Constructs: Burden

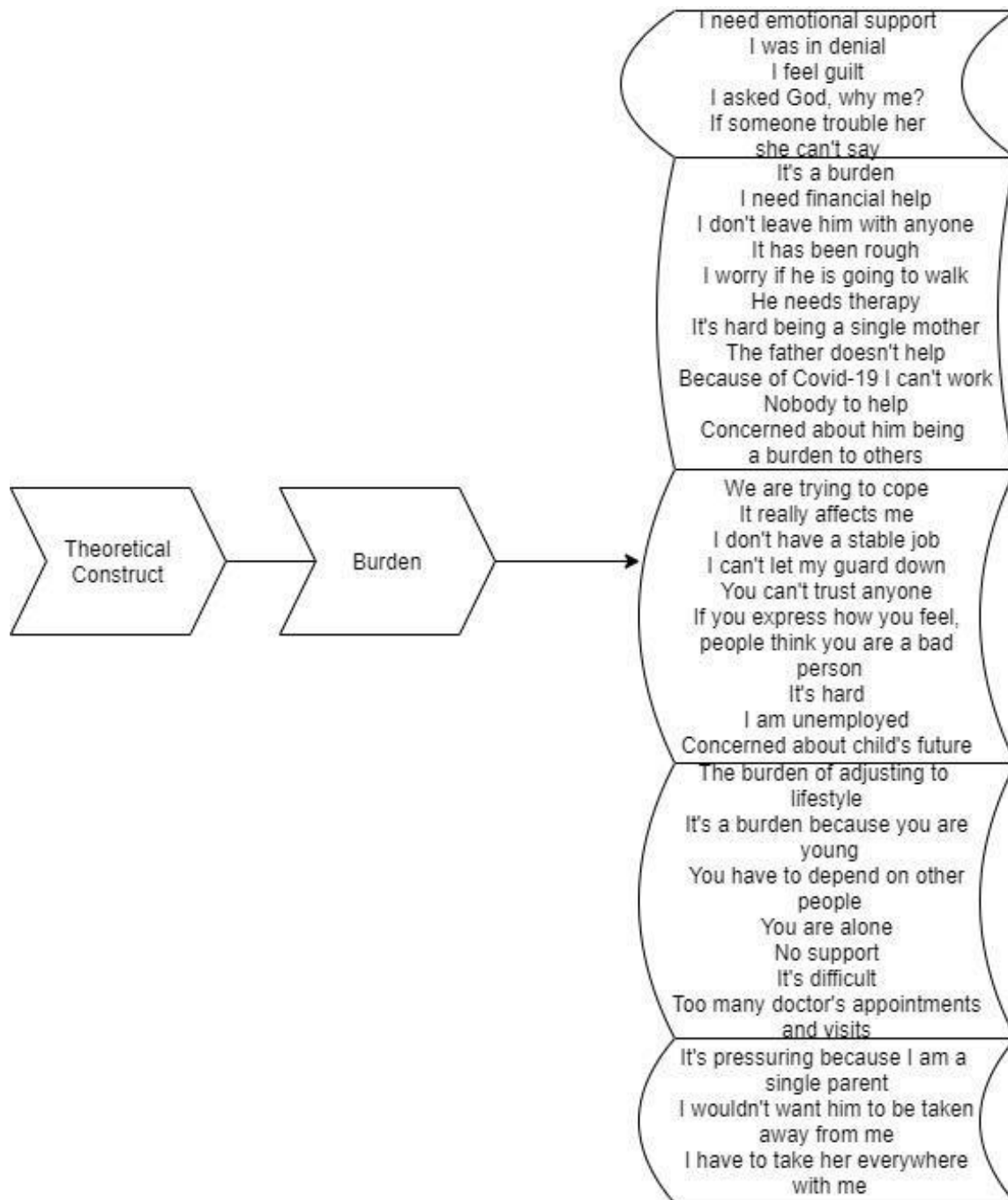


Figure 4: Theoretical Constructs: It's Challenging

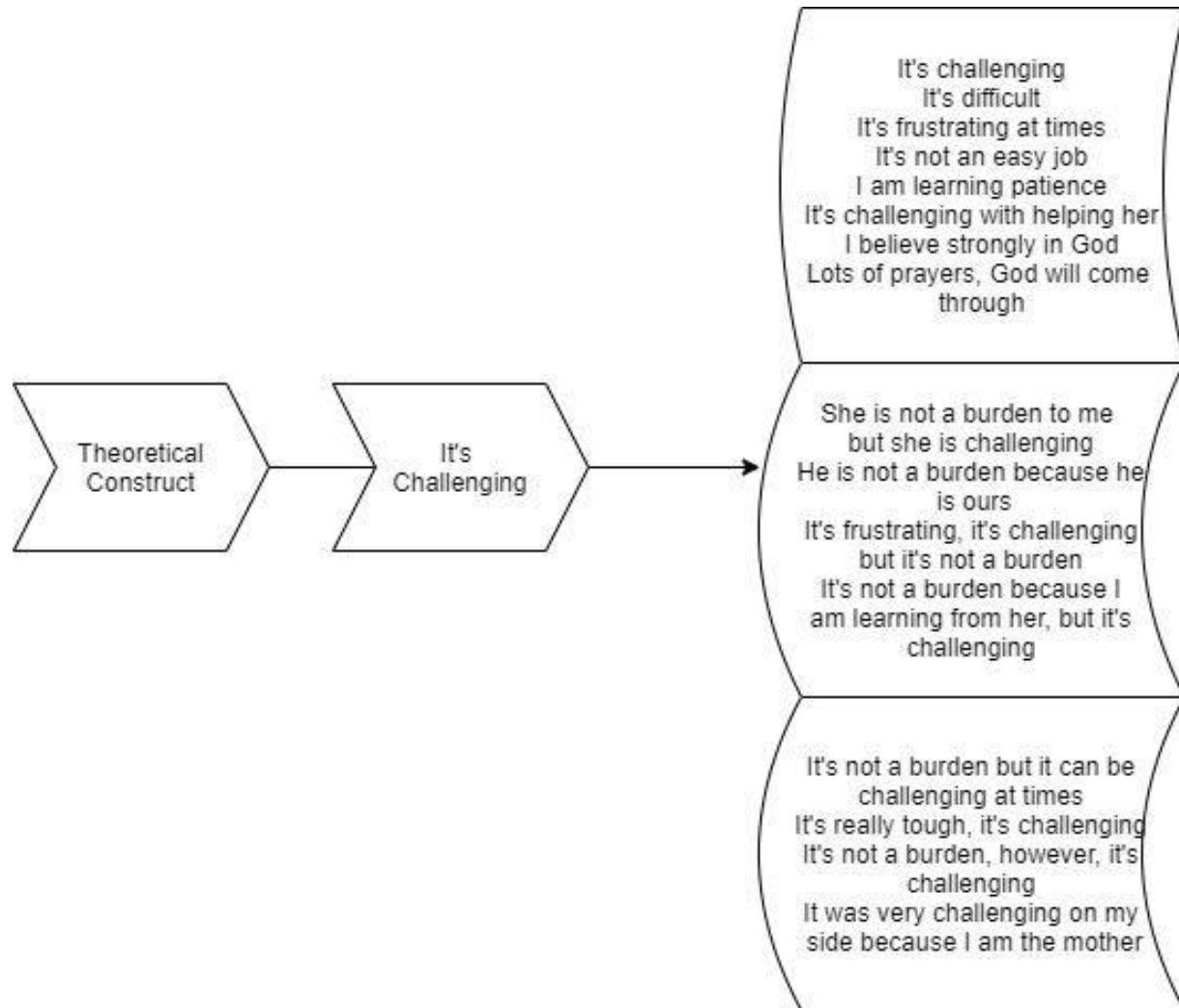


Figure 5: Theoretical Constructs: Emotional and Mental Wellbeing

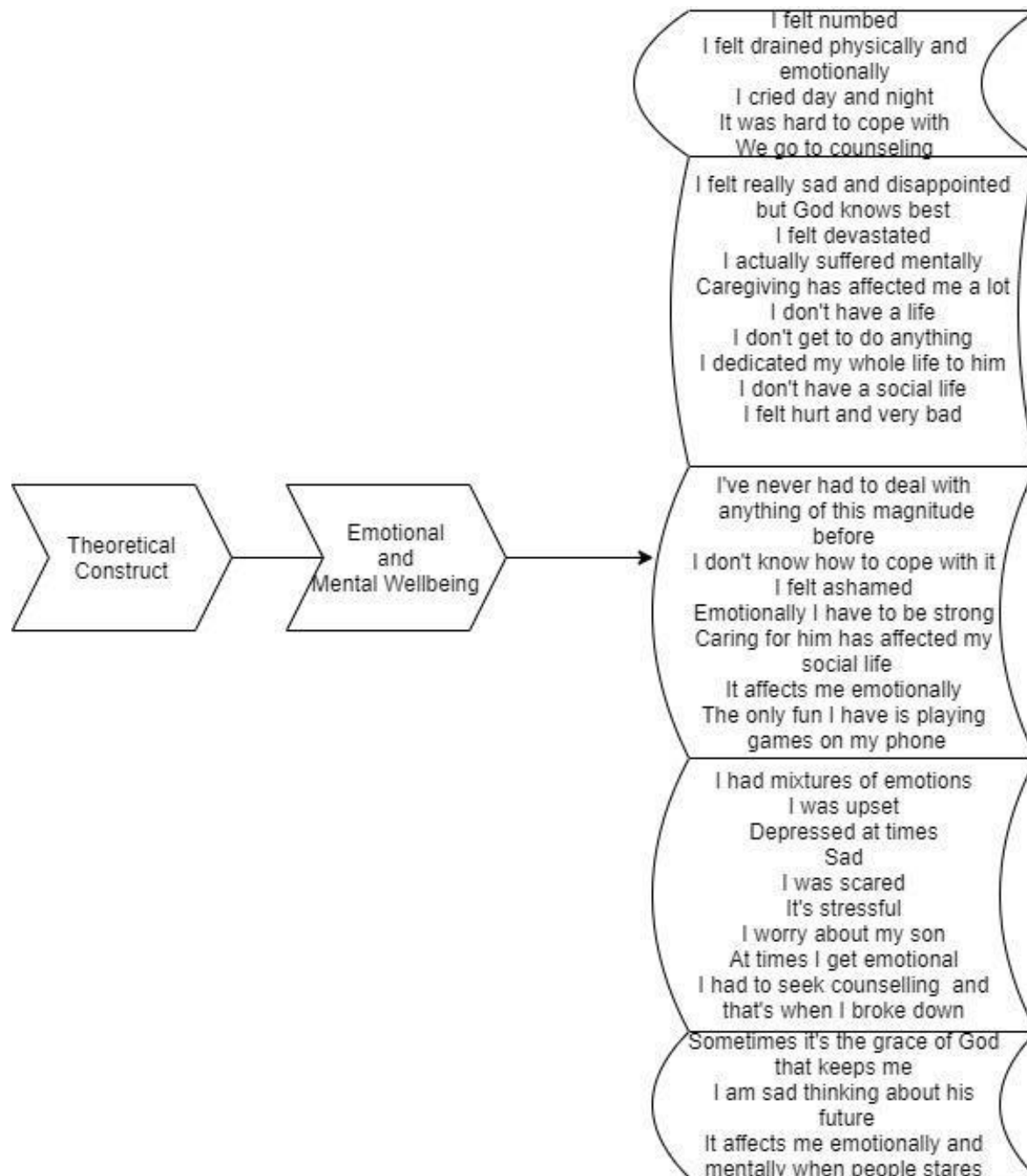


Figure 6: Theoretical Constructs: Professional Awareness

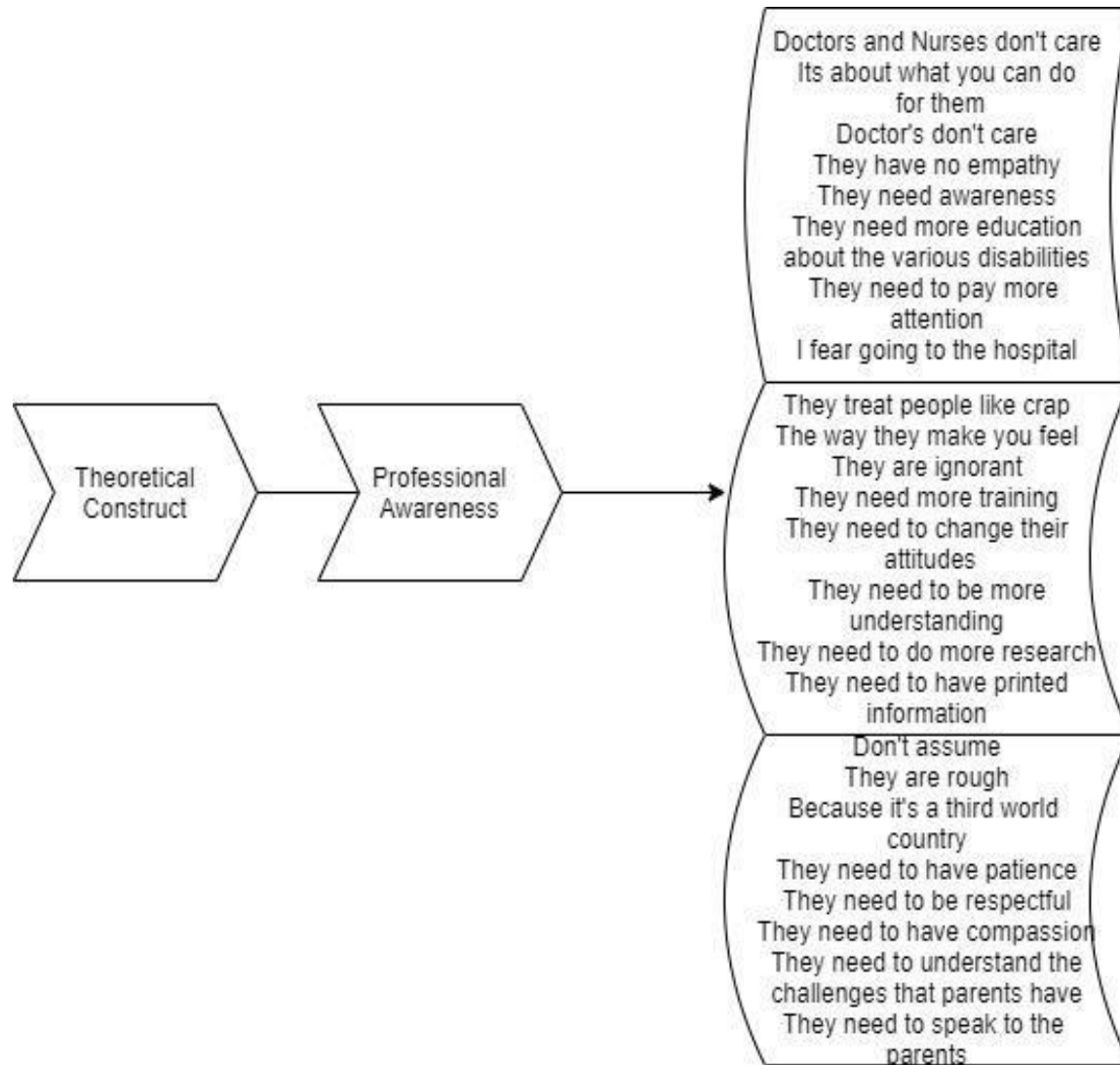
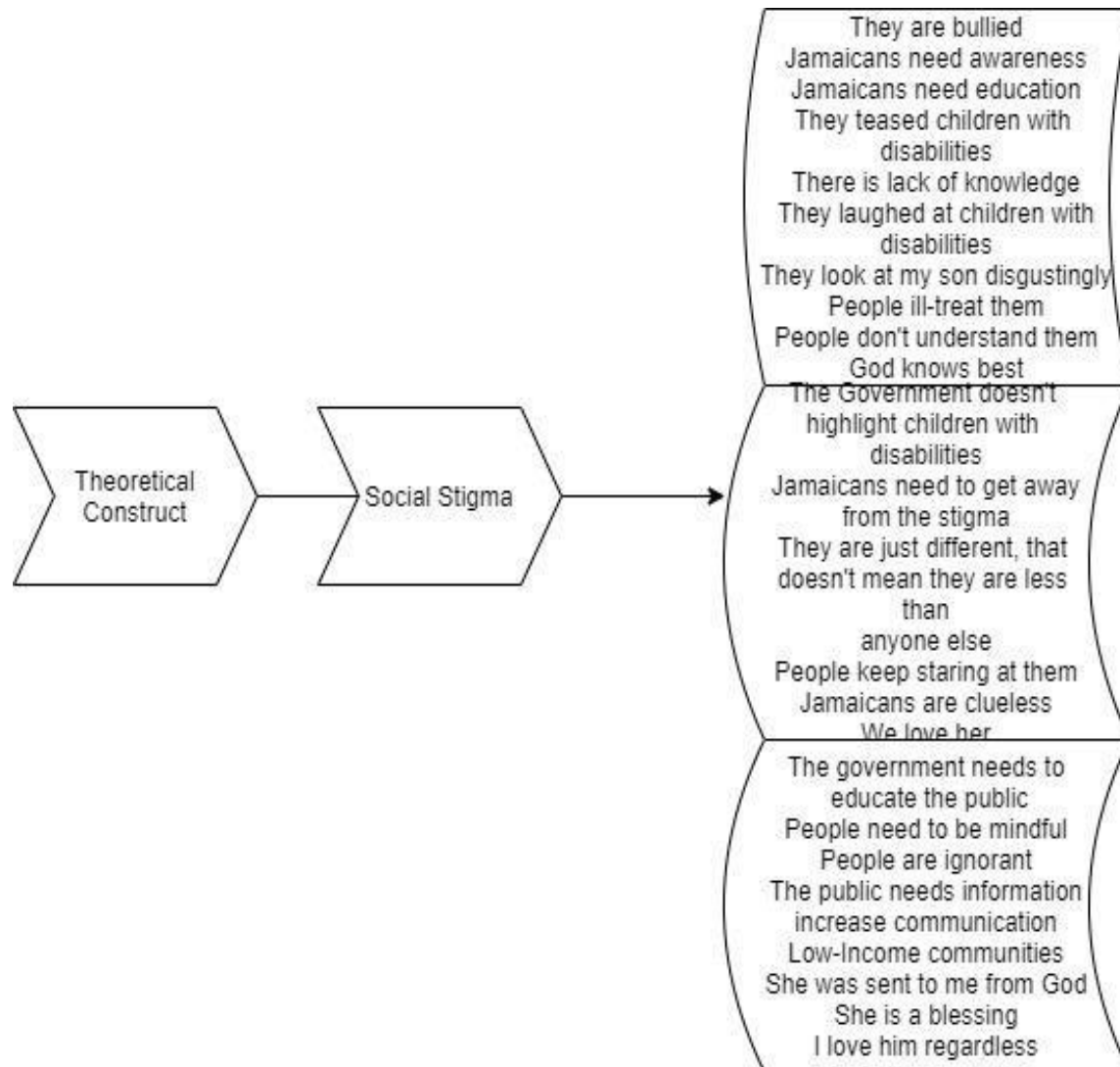


Figure 7: Theoretical Constructs: Social Stigma



Chapter 5: Discussion

Chapter 4 presented the key findings generated by the present study, identifying the critical components of the myriad challenges confronted by Jamaican parents of children with IDD. This final chapter of the study links the research findings to themes identified in the review of literature, examines each of the constructs that comprise the “challenges they face” (hereinafter referred to as simply the “challenges”), and explores contextual elements of parents raising IDD-diagnosed children in Jamaica within various theoretical contexts, especially that of Leininger (2002) with respect to the roles of culture, care, and diversity in nursing practice.

In this study, the finding of the core concept informed a concrete theory that describes and explains the experiences and challenges in raising children with IDD in Jamaica. It was revealed that parents encounter many challenges in raising children with a developmental disability in Jamaica. Parents are faced with the challenges of raising their children with a disability alone; some are faced with health issues and their own emotional and mental instability.

The parents who participated in the study were different in many ways such as age, gender, and social background. Although the parents were Jamaican and lived in Jamaica, their diversity was reflected in the experiences and challenges in raising their children with IDD. While there were differences, there were also shared elements in their experiences and challenges in raising their children with a disability living in Jamaica. During the interviews, the researcher was able to identify and interpret these shared experiences and challenges with five distinctive theoretical constructs including burden, it’s challenging, emotional, and mental wellbeing, professional awareness, and social stigma. Thus, the key finding was centered on the Basic Social Problem-Lack of Support and Services that led to the core concept of the challenges they face.

Central Constructs

Subsumed within the broader context of Challenges confronted by Jamaican parents of children diagnosed with IDD are the concepts of burdens, challenge itself, emotional and mental/psychological well-being, professional awareness, and social stigma. As Baker, Blacher, and Olsson (2005) commented, while there are certainly many individual variants in the experiences of parents of IDD-diagnosed children, there are also commonalities. Presented below is literature-driven analysis of the key components of Challenges that emerged from the interviews.

Basic Social Problem: Lack of Support and Services

The basic social problem and related burden experienced by parents raising children with IDD in Jamaica that unfolded from the data was the *lack of support and services*. The parents' experiences and challenges were significant with respect to raising their children with IDD, as is the case elsewhere (Budd, 2013; Coomer, 2013).

Through this research, it was identified that parents raising children with intellectual and developmental disabilities needed support and services when the theoretical constructs converged, leading to the core concept of *the challenges they face*. Once this core concept had been identified, then the basic social problem of lack of support and services can be addressed (Budd, 2013).

Parents raising children with developmental disabilities have been previously investigated. Multiple studies set in different counties, cultures, and communities have been conducted (Budd, 2013). This study adds to our understanding as nurses of what needs to be done to improve the services offered to Jamaican children with IDD in order to assist their caregivers in managing the challenges, burdens, and stressors associated with disabilities within

the family system.

The Core Concept: The Challenges They Face

In this study, the finding of the core concept informed a concrete theory that describes and explains the experiences and challenges in raising children with IDD in Jamaica. It was uncovered that parents encounter many challenges in raising children with a developmental disability in Jamaica. Parents are faced with the challenges of raising their children with a disability alone, some are faced with health issues and their own emotional and mental instability. The parents who participated in the study were different in many ways such as age, gender, and social background. Although the parents were Jamaican and lived in Jamaica, their diversity was reflected in the experiences and challenges in raising their children with IDD. While there were differences, there were also shared aims in their experiences and challenges in raising their children with a disability living in Jamaica. During the interviews, the researcher was able to identify and interpret these shared experiences and challenges with five distinctive theoretical constructs including burden, it's challenging, emotional and mental well-being, professional awareness, and social stigma - which led to the core concept of *the challenges they face*.

Burden: The Many Burdens Parents Identified

The parental participants expressed a sense of encountering many specific burdens as they attempted to raise their child with IDD. They expressed a great need for financial help and the need to be able to afford necessities for their child with IDD. Some parents stated that their financial ordeal stems from the fact that they are unemployed, others are raising their child alone with little or no help from the father, while others based their financial burden on the Covid-19 pandemic (Grael & Adabbo, 2011; Jamaican Information Service, 2007). Some

parents expressed the worry of their child becoming a burden to others. The burden of guilt was another factor as parents blamed themselves for the reason of their child's disability.

Parents raising children with IDD living in Jamaica need assistance with the challenges they face.

The parents acknowledged that the government subsidies provided by the Programme of Advancement Through Health and Education (PATH) are a conditional cash transfer program funded by the Government of Jamaica and the World Bank, with the aim of delivering benefits by way of PATH cash and bursary grants to the neediest and vulnerable in the society, is not sufficient to care for their child with an IDD (Jamaica Association on Intellectual Disabilities, 2019; Jamaica Information Service, 2019). To be qualified for the PATH program, the applicant must satisfy the eligibility criteria of being a member of a low-income or poor family residing in Jamaica. However, parents spoke about the long process and the bureaucracy of applying. Some parents mentioned that their applications were rejected even though they are raising a child with IDD and are unemployed (Planning Institute of Jamaica, 2009; Wilson-Harris, 2016).

The parents expressed concern that as they age, they will be faced with concerns of who will care for their child with an IDD if they become ill or die. With some financial assistance, parents expressed that they would be able to provide comfortable care for their child with a developmental disability. Parents realized that they need financial, emotional, and physical assistance to care for their child with IDD with the challenges they face.

Jamaica is very much a developing country and as such confronts many difficulties in addressing the burdens of parents of children with IDD. There is a lack of literature on the delivery of services to these children and their caregivers in most communities (Adnams, 2010).

There are few schools in Jamaica that are capable of serving children with disabilities, and those few schools where the staff are available to meet the needs of this population are overcrowded (Wilson, 2011).

A program initiated in 1975 by the Ministry of Labor and Social Security's Early Stimulation Program now serves 105 children with special needs including IDD (Patterson, 2012). It is clear from the commentary of the participants in this study that there are inadequate services in Jamaica, which add to the overall burden experienced by parents, families, and individuals who themselves have some type of IDD. Caregiver burden as described by Stucki and Mulvey (2000) is a multidimensional response to physical, psychological, emotional, social, and financial stressors that inevitably accompany the caregiving experience (Jones, 1996).

It's Challenging

The overarching construct emerging from the present study centers on the broad components of the challenges faced by these Jamaican parents. The greatest challenge seems to be the lack of financial means for properly caring for children followed by the lack of accessible programming (Jamaica Information Service (2019); Coomer, 2013; Deater-Deckard, 2004).

These challenges are often exacerbated by the culture of Jamaica which is extremely diverse with respect to race, ethnicity, religion, and attitudes toward people with disabilities. The Planning Institute of Jamaica (2009) has acknowledged that there are significant deficits in terms of programs specifically targeting children with IDD and that the country remains prone to stigmatization against individuals with disabilities despite the fact that there are several laws designed with the goal of protecting vulnerable populations. Culture in and of itself invariably affects the ways in which parents and relatives react to the presence of a child with the diagnosis of IDD (Marsack-Topolewski & Church, 2019). When there are biases present in any society

toward children who are disabled, Neely-Barnes and Dia (2016) acknowledge that the challenges parents face are multiplied significantly.

Emotional and Mental Well-Being

Both the literature reviewed above and the series of parental interviews indicated that parents of children diagnosed with IDD experience emotional difficulties as they attempt to cope with the multiple needs of their entire family (Samms-Vaughan, 2019). For many such parents, isolation and an inadequate social support system are instrumental in adding to the challenges of parents facing the necessity of coping with the needs of children with various pervasive developmental disorders (Mann, 2013). Unfortunately, the literature on raising a child with IDD tends to be somewhat limited in the context of Jamaica, although research suggests that as many as 200,000 Jamaicans of all ages live with a disability of some type (World Bank, 2016). Most of the studies that have been done on issues surrounding IDD in Jamaica have focused as did Mann (2013), Thorburn (2008), and the Jamaican Information Service (2019) on the incidence of IDD, type of IDD, and service availability.

Wilson-Harris (2016), however, argued that attention needs to be given not only to the emotional and mental well-being of individuals with IDD but also to their caregivers. Many of the participants whose comments are outlined in Chapter 4 expressed frustration that was an artifact not only of social isolation but also of inadequate financial support, educational services, and therapeutic interventions targeting both the child and the family system. This is perhaps all too common in developing countries such as Jamaica (Convention of the Rights of Persons with Disabilities, 2018; Deater-Deckard, 2004; Gill & Liamputtong, 2011). Interestingly, the parents participating in this study almost universally expressed a sense of panic, stress, depression, hurt, and shock when informed that their child had an IDD. Most felt that they were inadequately

prepared to address the multiple issues that would be likely to emerge as such a child matures.

Professional Awareness

The literature also acknowledges that even many professionals in the medical, psychological, and educational environments have limited knowledge regarding the different types of IDD that exist and the challenges that these children and their parents face (Deater-Deckard, 2004). Caregiving research, as described by Hunt (2003), has often tended to focus on the needs of children or patients rather than the needs of caregivers per (Kasuya, Polgar-Bailey & Takeuchi, 2000) much fewer professionals who work with families in which IDD is present (Leininger, 1991; Leininger & McFarland, 2002; Parnes, Cameron, Christie et al., 2009). A Knowledge, Attitudes, Practices, and Behavior study was commissioned by the Jamaica Council for Persons with Disabilities in 2015 to measure the awareness, values, and practices toward PWDs in Jamaica (Moncrieffe, 2015). The initial study comprised a sample of 1,500 respondents selected from all parishes across the island.

A much smaller sample (600 respondents) was selected to provide specific insight into the attitudes, knowledge, and practices of professionals perceived to engage more directly with the disability populace. In assessing the knowledge, attitudes, and behaviors toward PWDs. However, the data showed that participants had a low level of knowledge of disabilities, which was in part attributed to the inadequate and inconsistent dissemination of information. Most respondents (66%) stated they had either never received any information on disabilities or that the information was obtained too long ago to recall. This lack of knowledge was further reinforced by the consistently high numbers who were unaware of the different types of disabilities. Over 65% of respondents reported having no to little knowledge of each type of disability examined in the study. Such professions included teachers, police officers, transport

operators, health workers, community development practitioners, front-line service providers, policymakers, government officials, and religious leaders. The majority of the sample (96%) indicated either knowing someone with a disability or living with a disability themselves. The need for professional awareness in Jamaica extends to educators, primary care physicians, therapeutic specialists, and parents themselves. The majority of parents in this study tended to express concern for their children and fears that they would not be able to provide those children with adequate personalized care to facilitate the best outcomes in later life.

Social Stigma

Negative terminologies such as “dumb,” “invalid,” “handicapped,” or “abnormal” are often used to describe persons with disabilities living in Jamaica. There is a very real need in Jamaica to educate society as a whole on the question of social stigma against persons with disabilities (Morris, 2019; Nathan Ebanks Foundation, 2019a, 2019b). The literature acknowledges that the negative attitudes and prejudices surrounding the capabilities of the individual are a significant barrier to the full inclusion of people with a disability into Jamaican society. The World Bank (2016) stated that there are high levels of stigma by the general public and employers regarding persons with disabilities and their abilities, which often reinforce the social exclusion faced by this population. Significant research has been done on the stigma and discrimination often experienced by persons with disabilities globally, particularly in relation to those with mental illnesses (Corrigan, Thompson, Lambet, et al., 2003; Sharac, Mccrone, Clement & Thornicroft, 2010). Research conducted locally has also pointed to prevailing issues surrounding the knowledge, attitudes, and behaviors toward PWDs, revealing undertones of ignorance, prejudice, stereotypes, and discrimination (Anderson, 2014; Gayle & Palmer, 2005; Gayle-Geddes, 2016).

A study conducted by O'Toole (2001) across 13 Caribbean countries identified negative attitudes as a key factor that led to families with children with disabilities often feeling excluded from society. Such negative attitudes and perceptions resulted in PWDs becoming “familiar with social separation and courtesy stigma, abandonment, untenable circumstances in homes (such as being hidden and receiving ill-treatment), deprivation of independence and privacy, and vulnerability to psychoemotional, sexual, and physical abuse, as well as other discriminatory treatment” (Gayle-Geddes, 2016, p. 43).

Theoretical Frameworks

Several theoretical frameworks were instrumental in shaping the present study. These include symbolic interactionism, grounded theory, and Madeline Leininger's 2002 theory of culture, care, diversity, and universality as it relates to the nursing process. This section describes these theories in the context of the responses that were provided by the study participants.

First, grounded theory, in general, was employed as a practical guide through qualitative analysis (Charmaz, 2006, 2012). Grounded theory is a systematic methodology that is applied primarily to qualitative research in the social sciences. It tends to begin with a question such as that posed in this study, move to the collection of data that is relevant to the question, analysis of that data through coding by placing incidents or concepts into categories, and then the arrangement of these categories in hierarchies of significance (Creswell, 2013; Glaser & Strauss, 1965).

A grounded theory emerges from the data but it may, in fact, be derived in part from preexisting theories. Glaser (1967, 1992) points out that grounded theory may derive some fundamental assumptions from previously tested and validated theoretical approaches such as that of symbolic interactionism and the nursing theory of Leininger (1991). It is best used in

terms of a naturalistic inquiry that Lincoln and Guber (1985) view as permitting a researcher to work with a semi-structured interview framework using multiple probes to elicit nuanced information from participants.

When one is focusing on caregiving research, Hunt (2003) makes the case that, knowingly or not, most researchers begin with a specific perspective on the issue. Since grounded theory involves thematic analysis, it can be used within several theoretical frameworks (Glaser & Strauss, 1965). For this reason, both symbolic interactionism as discussed below, and Leininger's (2002) nursing theory were employed.

Symbolic Interactionism

The core concept *-the challenges they face-* aligns with Blumer's (1969) theoretical perspective of symbolic interactionism. This is a social theory about human behavior and inquiry into human conduct. It proposed that the meanings of things come from social interaction with others via the interpretation with others of shared or similar experiences. Key propositions of the theory identified by Blumer (1986) are

- Humans act toward things on the basis of the meanings that things have for them.
- The meanings of such things are derived from social interactions that one has with one or more "others."
- These meanings are refined through an interpretive process used by the person dealing with the things or experiences they encounter.

Understanding how Jamaican parents raising children with IDD requires an interpretive process on how the parents deal with the challenges they encounter; consequently, one must determine the extent to which interaction with others in society or the family impacts such behaviors (Blumer, 1986).

In this study, interviewees revealed that parents dealt with the challenges based on the meaning the process holds for them. The meaning of the process and the implications of the challenges of raising children with IDD occurs over time as the parents make meaning, sense, and define their experience and challenges in raising children with IDD. The meaning of their experiences and challenges are revealed by examining their interpretation of their experiences, the decisions they make, and how they dealt with the challenges (Duncan, Coatsworth, & Greenberg, 2009).

Plant and Sanders (2007) commented that various stressors are unavoidable in families wherein one or more members has a diagnosed IDD or other chronic physical or mental health problems. Among those stressors are the reactions of others to the child, the family, and the problem (Samms-Vaughan, 2019). The World Health Organization (2005, 2011) has suggested that regardless of the nature of a society's culture, disabilities are viewed as having primarily negative consequences for individuals, society, and families. Nevertheless, the parents participating in this study seemed to believe that despite the various challenges and burdens they faced - from financial deficits to poor services and limited access to social stigma and marginalization – their children were loved and valued members of the family constellation.

Leininger's Culture, Care and Diversity Nursing Theory

Central to this study, which was undertaken in response to the requirements of a nursing curriculum, is Madeleine Leininger's (2002) theory of culture care. Leininger (2002) created a theory identifying a lack of cultural and care knowledge as the missing component within nurses' understanding of the many variations that are required inpatient care to support compliance, healing, and wellness. It calls for providing culturally congruent care through cognitively based assistive, supportive, facilitative, or enabling acts and decisions that are individualized

(Leininger & McFarland, 2002).

For a nurse who follows Leininger's (2002) theoretical orientation, it is important to establish a nurse-patient relationship in which the nurse and the client creatively design a new or different care lifestyle that is designed to promote health and well-being. Often, as is the case with children with IDD, this theory focuses as much on parents as it does upon children themselves. It is consistent with the regulations put in place for protecting Jamaica's children and knowledge of what life for Jamaican parents of children with disabilities is likely to involve (Samms-Vaughan, 2019).

Acknowledging that parents of children with IDD in a developing country are likely to be challenged by many different variables, Leininger (2002) developed a model that became a movement called transcultural nursing. It is understood as a substantive area of study and practice that is focused on comparative cultural care, values, beliefs, and practices of individuals and groups based on their culture. The fundamental concepts of Leininger's (2002) theory are:

- Care assisting others with real or anticipated needs represents an effort to improve a human condition of concern.
- Caring consists of actions and activities directed toward providing care.
- Culture consists of learned, shared, and transmitted values, beliefs, norms, and lifeways to a specific individual or group that then shapes their thoughts, actions, and values.
- Culture care consists of multiple aspects of culture that combine to assist a person or group to improve their human condition.
- Culture care diversity embraces the differences in meanings, values, or acceptable forms of care in or between groups of people.

- Culture care universality reflects Leininger's (2002) acknowledgment that there are commonalities regarding illness, death, and disabilities across many cultures.
- The nurse using the culture care diversity theory described by Leininger and McFarland (2002) as well as Hunt (2003) becomes knowledgeable regarding and sensitive to the nuances of cultural attitudes, beliefs, and actions and structural interventions to respond affirmatively to those variables.
- Leininger's (2002) culturological assessment is designed to provide a holistic, comprehensive overview of the client and family system addressing communication and language, gender, sexual orientation, meanings attributed to a disability, age, socioeconomic status, and interpersonal relationships among other variables.

The goal of Leininger's (2002) model is to sensitize nurses and other caregivers to the reality of how culture in and of itself helps or hinders the caregiving process and what nurses and other healthcare practitioners should do to maximize positive outcomes for their clients. This includes acknowledging mindful parenting as described by Duncan, Coatsworth & Greenberg. (2009) as well as the effects of caregiver burden on coping ability and the potential for burnout (Kasuyas, Polgar-Bailey & Takeuchi, 2000).

Applying Leininger's (2002) theory in the case of nursing care for children in Jamaica diagnosed with IDD and their parents is critical. The parents who participated in this study acknowledged that they felt, to some extent, that their needs and concerns were given inadequate attention and that because this was the case, the challenges they confronted and the burdens they bore were more damaging than necessary. Parents of children with IDD denied feeling excessively burdened while still acknowledging the challenges they faced. In responding to questions about programs available for them and their children in Jamaica, they almost

universally acknowledged that such services were overly limited, not accessible throughout the country, and in some cases, unaffordable (Jamaica Association on Intellectual Disabilities, 2019; Jamaica Information Service, 2007, July 15; Mann, 2013).

Assistance for special needs individuals regardless of their age is vital if those individuals are to maximize their capacity for meaningful growth and development and improving the overall status of family well-being (Parnes, Cameron, Christie, et al., 2009). Adapting existing programs offered by groups such as the Nathan Ebanks Foundation (2019a, 2019b) as well as the programs of the Planning Institute of Jamaica (2009) to include Leininger's (2002) theories would be of special value going forward with respect not only to service delivery but also policy development itself.

Limitations of the Study

At the outset of this study, a methodology was proposed that included a grounded theoretical foundation that would lead to a set of interviews designed to identify the challenges and burdens faced by Jamaican parents of disabled children. Appendix E contains the specific questions and probes that were used in interviewing a total of 21 subjects chosen through a purposive sample that was obtained through recruitment and snowballing, a number that Charmaz (2006) described as adequate. The small size of the sample was a limiting factor, as was the limited variety of IDD conditions and diagnoses that were identified by caregivers.

The broad array of disabilities ranging from Dandy-Walker Syndrome, Hydrocephalus, Down Syndrome, Autism Spectrum Disorders, Spina Bifida, speech and hearing impairments, cerebral palsy, and other physical disabilities prohibited any meaningful attempt to correlate parental experiences with a specific disability. In order to do that, a study would need to be conducted that focused on one IDD such as autism spectrum disorder that impacted 5 of the 21

subjects in the present study. Other frequently identified disabilities were cerebral palsy and Down Syndrome. A much larger sample would be of value in differentiating between the experiences of parents with children suffering from differing or varying IDD.

There may be concepts in the data that were not fully identified that also impact the challenges that caregivers face and their capacity for addressing those issues. Ultimately, as Table 1 demonstrates, the sample was fairly homogeneous and one which is more than adequate to answer a broad overview of questions regarding the difficulties experienced by Jamaican parents of children with IDD.

Implication for Nursing Practice and Policy

The study confirms the assertion that Leininger's (2002) transcultural nursing theory would be valuable in providing the theoretical and practice framework for interventions and policies targeting the nursing care of Jamaican children with IDD. The Jamaica Association on Intellectual Disabilities (2019), the Jamaica Information Service (2019), and private sector organizations such as the Nathan Ebanks Foundation (2019a), and the Jamaica Down Syndrome Foundation (2019) have played a key role in assisting the Planning Institute of Jamaica (2009) in developing a more comprehensive approach to providing care for children and families experiencing IDD.

The study highlights the fact that the Jamaican Association on Intellectual Disabilities (2019), the Jamaican government (Jamaica Information Service, 2019), and the Planning Institute of Jamaica (2009) are well aware of the many needs of Jamaican children with IDD – needs that are in many instances going unserved. Organizations such as UNICEF (2007) and the World Bank (2016) have explored these issues in some depth and offered assistance to the government of Jamaica. While this has been extremely helpful, and while one must

acknowledge that Jamaica faces a plethora of socioeconomic problems and unmet needs, it is probable that inadequate attention is being given to this particular subject.

Implications for Future Research

Several viable avenues for additional research have been identified in this study. First, a larger sample of subjects would be highly desirable and could permit comparisons between the lived experiences and challenges faced by Jamaican parents of children with specific IDD. This study does not permit any correlation between disability, parental marital status, and children's ages in addition to other variables. It would be extremely valuable to examine such relationships going forward in order to facilitate improvements to the policymaking and service delivery processes.

Conducting research that narrowly focuses on a quantitative examination of the number, types, and prevalence of both disabilities and targeted solutions in both the rural and urban environments would be valuable. Future research should assess the specific services that provide effective assistance to Jamaican children with IDD and their families. This kind of research is unfortunately lacking at the present time.

Summary

This chapter has offered a narrative assessment of the findings generated by a qualitative grounded theory study of the challenges faced by parents in Jamaica raising children diagnosed with an IDD. As a suitable conclusion to the entire study, it emphasizes the relationship of various theories and particularly that of Leininger (2002) to the question of how services should be structured to maximize positive outcomes for members of the target population. Qualitative studies as described by Babbie (2020) as well as Creswell (2013) are inherently exploratory in design rather than explanatory. The next step is to focus more narrowly on the explanation of

strategies of a practical nature that can be employed in Jamaica to ease the challenges that are confronted by families with a child diagnosed with an IDD. This kind of research is essential in that it paves the way for the development of potentially successful and mindful program delivery.

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Appendix A: Research Flyer

Parents Raising Children with Developmental Disabilities in Jamaica

SEEKING PARTICIPANTS FOR A RESEARCH STUDY

The purpose of this research study is to understand the experiences and challenges of parents of school aged children with developmental disabilities who are living in Jamaica.

To participate in this research, you must:

- Be a parent caring for your school aged child aged 4-18 with a developmental disability (Guardian or Grandparent in the same household may also participate)

Participation in this study involves:

- A time commitment of an approximately 1–2-hour interviews by telephone, email, WhatsApp, Facetime, Zoom or Skype
- A gift card worth \$25 USD will be given for your participation

**To find out more information about this study,
please contact Maureen Lowers-Roach:**

- **Phone: (US 1) 516-817-7497**
- **Email: MLowers-Roach@lions.mollov.edu**
- **Jacqueline Hylton-McLean**
- **Email: mcleanjacqueline@rocketmail.com**
- **Phone: (JA 1) 876- 892-5281**

[illegible]

Appendix B: Interviewer Script

Hi, my name is Maureen Lowers-Roach.

I am a registered nurse and also a doctoral nursing student at Molloy College in Rockville Centre, New York. I am in the doctoral program working toward my PhD in nursing.

I am doing a research study as part of my education at Molloy College.

The research topic concerns the caregiver experience of parents of school-aged children who have developmental disabilities and are living in Jamaica.

My research goal is to understand the challenges that parents may be experiencing.

Your participation is completely voluntary and you may say no if you do not want to participate.

If you agree and we start talking and you decide you no longer want to do this, we can stop at any time.

Your confidentiality is assured. I will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written reports about this study.

If it is okay with you, I might want to use direct quotes from you, but these would only be cited as from a person without your real name.

There is no expected risk to you for helping me with this study. There are no expected benefits to you either.

Do you have any questions for me?

Do you still want to do the interview with me?

Appendix C: Consent

Molloy College INFORMED CONSENT TO PARTICIPATE IN RESEARCH

You are being asked to volunteer to be a participant in a research study.

Title of Research: Parents raising Children with Developmental Disabilities in Jamaica

Researcher: Maureen Lowers-Roach, MBA, RN, who is conducting this research as a doctoral student in the Barbara H. Hagan School of Nursing, Molloy College, 1000 Hempstead Ave, Rockville Centre, NY 11571 USA

Contact email: MLowers-Roach@lions.molloy.edu

Purpose of the Study: The purpose of this study is to understand the experiences of parents who are raising a school-aged child with developmental disabilities and are living in Jamaica.

Expected Duration of the Study: The study will last for approximately 12 months while the researcher will interview a sufficient number of participants and analyze the collected information.

Description of Procedures: You will be able to review the suggested study questions to help you decide if you want to participate in this study. After signing this Molloy College Institutional Review Board approved consent and all your questions are answered, you will schedule an individual interview with the researcher at a time and method for your convenience. The interview may be done over the telephone, through email or by Internet methods such as Skype or Facetime. The following procedures will then be completed:

(1) Interview: Audio-tape recorded interview with the researcher lasting approximately 1-2 hours by telephone or Internet methods such as Skype or Facetime. Email interactions should take approximately the same amount of time (2) Follow-up Contact: is requested to allow you to elaborate on responses and for the researcher to clarify the understanding of the interview. This

will take place at your convenience and choice of contact method to be by email, telephone, or Internet, from 1-4 weeks after the initial interview and should take less than 30 minutes of your time.

(3) Final write-up: Confidentiality will be assured in all written materials through the use of participant pseudonyms (not your real name) and no personal identifying data revealed such as place of work or your child's name. You may request a copy of a final study summary.

Possible Benefits: A \$25.00 USD gift card will be given to you after the completion of your interviews for your time and willingness to participate. There are no other direct benefits from your participation. It is possible that you may appreciate having the opportunity to talk about your experiences. It is hoped that the knowledge gained from this research will be of benefit to others in the future.

Reasonably Foreseeable Risks/Discomforts: There are no research-related risks or psychological discomforts anticipated. It is possible that you may feel tired from talking or writing emails for 1-2 hours. You may stop the discussion at any time or reschedule your interview. Although every reasonable effort has been taken, breach of the protections in place to maintain confidentiality cannot be guaranteed. We will minimize any risks of confidentiality breach by coding of transcription data on interviews with only pseudonyms. This way, while information will not be anonymous, it will be coded decreasing risk to your data confidentiality.

Conditions for Participation – Parents of school aged children (ages 4-18 years) with a developmental disability and living in Jamaica may participate in the study. Grandparent caregivers living the same household involved in the direct care of the child may also participate.

Voluntary Participation/Withdrawal: Your decision as to whether or not to take part is completely voluntary (of your free will). If you decide to take part in the study, you may withdraw at any time. Any information you have contributed may also be excluded if you so

choose. Your refusal or discontinuation at any time will be without penalty.

Costs/Compensation: There are no costs involved or interference with your child's care.

How confidentiality will be maintained: You will be identified only by a pseudonym (another name assigned to yourself and to your child). Your personal information and signed consent will be kept confidential. Your name will not be reported in any publication. Only the data obtained as a result of your participation in this study will be made public. Personal identifiers such as addresses, workplace, or health care providers will not be used in any publication. Email communication will be kept confidential and deleted after read and transcribed by the researcher to a secure study file without any personal identifiers. To ensure that this research activity is being conducted properly, Molloy College's Institutional Review Board (IRB), whose members are responsible for the protection of human subjects' rights for all Molloy-approved research protocols, have the right to review study records, but confidentiality will be maintained as allowed by law.

Use of Audiotapes in the Study: Interviews conducted by telephone or live Internet methods such as Skype or Facetime will be audio taped, with your permission, to aid the researcher in obtaining an accurate account of your intended communication. Tapes will be labeled only with a code number, which will be kept locked in the researcher's files. You may, at any time, review your audiotapes and ask that all or any portion of the recording be erased. The audiotapes will be reviewed by the researcher and will be transcribed into a written or computer document for review. The tapes will be destroyed upon the completion of the study.

Voluntary Participation: An explanation of the procedures to be employed in this study in which I have voluntarily agreed to participate has been offered to me. All my inquiries concerning the study have been answered to my satisfaction. I understand that the information collected will be held in confidence, and that my name will not in any way be identified. I understand that additional information about the study results will be provided, at its conclusion, upon my request. I know that I am free to withdraw from this study without penalty at any time. The above information has been provided to me (check one)

_____In writing _____Orally

Signature of participant

Date

I also consent to audio recording of my interview(s)

Signature of the participant _____ Date _____

Signature of researcher _____ Date _____

Complete the following if you wish to receive a summary of the results of this study:

NAME (Typed or printed): _____

e-mail _____

Contact for Questions About the Research:

You may contact the researcher (Maureen Lowers-Roach) by telephone, email, or in writing:

MLowers-Roach@lions.molloy.edu (USA-1) 516- 817-7497 or my Doctoral Dissertation

Chairperson for this research study, Dr. Susan Vitale PhD RN NP.

Address: Barbara H. Hagan School of Nursing and Allied Health Services, Molloy College, 1000 Hempstead Ave, Rockville Centre, NY 11571, USA, Telephone (USA-1) 1– 516-323-3000

Appendix D: Demographic Inventory

Please fill in the blank or circle the appropriate answer

1. What is your age_____
2. Are you the Mother, Father, or Grandparent of the child with a disability?

3. What is your marital status (circle one)
Married
Divorced
Single (never married)
Widow
Separated
4. Number of children you have_____
5. List the ages of all child dependents in your home (Do not indicate name but list by ages)
Males _____ Females _
6. Age of child with disability_____
7. Gender of Child with disability (Circle)
Male
Female
8. Who else is living in the home with you and your child with the disability (Spouse, Aunts, Uncles, Nieces, Nephews, Grandparents, Friends)?

- 9 Your highest level of education completed and any other training.
Primary _ Secondary_ Tertiary _____
1. What is your employment status and type of work/profession
Self employed
Permanently employed
Part Time employed
Not working outside the home
2. What is your source of income, if unemployed_____
3. What is you Religion_____

4. What financial costs are you facing from caring for your school aged child with physical disability? _____
5. Do you consider yourself as being financially secure or are you experiencing financial difficulties? Explain. _____
6. Describe who/what can you count on as a support _____
7. How do you identify as belonging to an ethnicity or race

8. List any health problems you have including physical or emotional conditions such as depression _____
9. Are there others in your family with health concerns or family members you care for? Describe _____
10. Describe/name your child's physical disability and if there are other disabilities such as intellectual, genetic, developmental delay _____
11. Describe if the child attends school and what type _____
12. Is your school aged child receiving assistance from the government? If yes, what type of assistance is your child receiving?
13. Does the child receive any therapy such as physical, occupational, speech etc? Describe _____
14. Does the child receive government financial support and if so what type?

15. What is your greatest wish for your child? _____

Thank you for your participation

Appendix E: Researcher Developed Interview Questions and Probes

1. What type of disability were you told that your child has?
2. How did you feel when you were told that your child has a developmental disability?
3. Tell me how you and your family have been affected by having a child with a developmental disability?
4. Tell me about your experiences in caring for your school-aged child with a developmental disability? Do you perceive caring for that child as a burden? Please describe.
5. Describe how caregiving affects you emotionally and mentally.
6. How has caregiving affected your family and social life?
7. Tell me about who or what is helping you in your daily life, with your responsibilities, and with the care of the child?
8. How do you cope as a caregiver for your child with a disability?
9. What resources are available in your community? Do you access any of these resources?
10. What kind of support do you need to help reduce the challenges of caring for your child?
11. What programs would you like to see put in place that will benefit parents of developmentally disabled school-aged children?
12. What should doctors and nurses be aware of so that they are better able to assist parents who are caring for school-aged children with a disability?

Appendix F: Some Definitions of Jamaican Words Spoken by Parents during Interviews

Feel away - Feeling badly about something

Pass the worse – When a child grows up and his ability to care for themselves Anybody – Anyone

Nobody – Anyone Chile - Child

I am down – Feeling depressed, sad

He didn't look anyway – He looked normal Never around her – Never present

Go to – Attend, visit It's rough – Its difficult

On my side – Related to me On his side – related to him

If someone troubles her – If she is abused I feel bad – I feel awful about the situation Used to – In the past

I cry day and night – I cry constantly

It about what you can do for them – Bribery

Tease – To make fun of someone in a distasteful way Ill-treat – To treat someone badly

Down there – At a place

Appendix G: IRB Approval From Molloy College



IRBNet Board Action

4 messages

Patricia Eckardt <no-reply@irbnet.org>

Wed, Oct 14, 2020 at 10:49 AM

Reply-To: Patricia Eckardt <peckardt@molloy.edu>

To: Maureen Lowers-Roach <mlowers-roach@lions.molloy.edu>

Please note that Molloy College IRB has taken the following action on IRBNet:

Project Title: [1603080-1] Parents Raising Children with Developmental Disabilities in Jamaica: A Grounded Theory Approach
Principal Investigator: Maureen Lowers-Roach

Submission Type: New Project
Date Submitted: May 4, 2020

Action: WITHDRAWN
Effective Date: October 11, 2020
Review Type: Administrative Review

Should you have any questions you may contact Patricia Eckardt at peckardt@molloy.edu.

Thank you,
The IRBNet Support Team

www.irbnet.org

Patricia Eckardt <no-reply@irbnet.org>

Wed, Oct 14, 2020 at 11:00 AM

Reply-To: Patricia Eckardt <peckardt@molloy.edu>

To: Maureen Lowers-Roach <mlowers-roach@lions.molloy.edu>

Please note that Molloy College IRB has taken the following action on IRBNet:

Project Title: [1670076-1] Parents Raising Children with Developmental Disabilities in Jamaica: A Grounded Theory
Principal Investigator: Maureen Lowers-Roach

Submission Type: Amendment/Modification
Date Submitted: October 11, 2020

Action: EXEMPT
Effective Date: October 14, 2020
Review Type: Exempt Review

[Quoted text hidden]

Appendix H: Approval Letter from Ministry of Health Ethics Committee in Jamaica

KINGSTON 5, JAMAICA, W.I.
Tel: (876) 633-7400/7433/7771/817
Website: www.moh.gov.jm

ANY REPLY OR SUBSEQUENT
REFERENCE SHOULD BE ADDRESSED
TO THE PERMANENT SECRETARY AND THE

Ref. No.: SRD/ETH/20
November 20, 2020

Mrs. Maureen Lowers-Roach
Principal Investigator
32 Putman Avenue
Roosevelt
New York 11575

Dear Mrs. Lowers-Roach,

RE: Parents Raising Children with Developmental Disabilities in Jamaica: A Grounded Theory
Approach

This serves to inform you that the Ministry of Health & Wellness Advisory Panel on Ethics & Medico-Legal Affairs has reviewed and approved Version 4 of the captioned study proposal. The study has been assigned the number 2020/35.

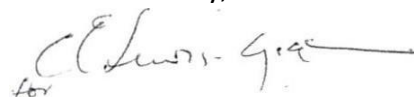
Attached, please find the approved cover page stamped and signed by the Ministry's Advisory Panel.

Please keep the Ministry updated regarding the progress and submit a summary of the results and conclusion on completion of the study.

Kindly note that should any changes be made to the proposal, the same should be re-submitted to the Advisory Panel on Ethics and Medico-Legal Affairs for reevaluation.

We wish you every success in this endeavor.

Yours sincerely,


for
Chairman

Advisory Panel on Ethics and Medico-Legal Affairs

Standards and Regulation Division

**Appendix I: Approval Stamp from Ministry of Health Ethics Committee in
Jamaica**

Molloy College

Barbara H. Hagan School of Nursing.

Ph.D. in Nursing

Parents Raising Children with Developmental Disabilities in Jamaica: A Grounded
Theory

Approach

A Dissertation Proposal

By

Maureen Lowers-Roach MLowers-Roach@lions.molloy.edu

(US 1) 516-817-7497

Local Investigator with Oversight/Supervision Jacqueline Hylton-McLean

mcleanjacqueline@rocketmail.com

(JA 1) 876-892-5281

Submitted in partial fulfillment of the requirements For the degree of Doctor of

Philosophy (November 26, 2020) Final Version

The Dissertation of entitled

Parents Raising Children with Developmental Disabilities in Jamaica: A Grounded
Theory Approach

MOH ETHICS COMMITTEE
Date Approved November 20, 2020
Date November 19, 2021

